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ABSTRACT

This report on Alzheimer's disease was written at the request of several committees of the United States Senate and House of Representatives. It begins with a brief overview of Alzheimer's disease and other disorders causing dementia and gives actual and projected figures on the incidence of such disorders in the United States. The goals of public policy related to dementia are explained and federal policy priorities, reasons for the increased interest in dementia, and policy interest in dementia are discussed. A section defining dementia presents symptoms of dementia and lists disorders that may cause dementia. The course of the dementia-causing illnesses is traced. The magnitude of the problem of dementia is considered, with sections looking at the prevalence of dementia and the costs of dementia, including overall costs; costs of diagnosis, drugs and medical services, nursing home care, and informal long-term care; and costs to the government. A section on coordinating services for those with dementia considers the care system; presents an inventory of services; and examines senior, acute care, long-term care, social, and mental health services. Groups of special concern are identified, including those without families, minorities, those experiencing dementia onset in middle age, rural populations, veterans, low income groups, and caregivers. Policy issues are considered in the areas of: (1) special programs for dementia; (2) diagnosis and treatment; (3) legal and ethical concerns; (4) education and training; (5) delivery of long-term care; (6) biomedical research; and (7) health services research. (NB)

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Congressional Summary

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CG 021102

LOSING A MILLION MINDS

Confronting the Tragedy of Alzheimer's Disease and Other Dementias

CONGRESS OF THE UNITED STATES
Office of Technology Assessment
Washington, DC 20510-8025

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Foreword

Congressional concern about the plight of those suffering from Alzheimer's disease and other dementias has steadily mounted for the past five years. This report grew out of a previous OTA report on *Technology and Aging in America*; it was requested by the following seven committees:

- **U.S. Senate:**
  - —Committee on Finance,
  - —Committee on Labor and Human Resources,
  - —Committee on Veterans' Affairs, and
  - —Special Committee on Aging.
- **U.S. House of Representatives:**
  - —Committee on Energy and Commerce,
  - —Committee on Science and Technology, and
  - —Select Committee on Aging.

In addition to the requesting committees, the House and Senate subcommittees that appropriate funds to the Department of Health and Human Services have frequently expressed interest, as have the Senate Committee on the Budget and the House Committee on Ways and Means. Members and staff of the requesting committees, other committees, and personal staff have been directly involved in identifying subjects that are covered in this report. The unusual length of this report is testimony to the diversity of issues associated with dementia that fall within the jurisdiction of various committees.

Writing this report involved collection of more than 10,000 pages of existing documents and preparation of more than 40 papers by outside experts under contract to OTA. OTA staff also gathered information through discussions with more than 130 congressional staff and hundreds of others—including government employees at the State and Federal levels and representatives of more than 100 nongovernment organizations in the United States and other countries. The resulting document has been reviewed by the project's advisory panel and more than 50 other experts in various relevant fields. More than 100 other individuals have reviewed specific chapters or early drafts.

On behalf of OTA, I wish to express my thanks to the myriad of individuals who contributed either directly or indirectly to this study. It distills a mass of information into a form that I hope will be useful to policymakers. As with all OTA reports, however, the content is the sole responsibility of OTA and does not necessarily constitute consensus of or endorsement by the advisory panel or the congressional Technology Assessment Board.

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NOTE: OTA appreciates and is grateful for the valuable assistance and thoughtful critiques provided by the advisory panel members. The panel does not, however, necessarily approve, disapprove, or endorse this report. OTA assumes full responsibility for the report and the accuracy of its contents.

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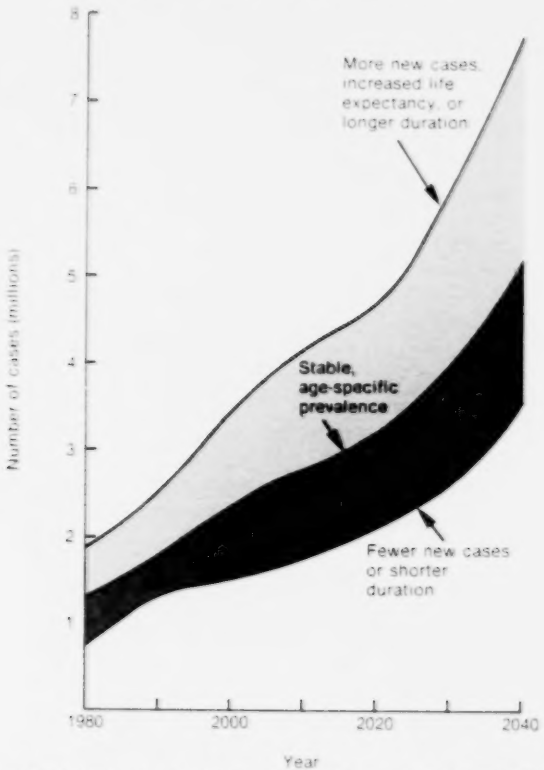
Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias

Disorders causing dementia—the loss of mental functions in an alert and awake individual—will constitute a large and growing public health problem until well into the next century. Today, an estimated 1.5 million Americans suffer from severe dementia—that is, they are so incapacitated that others must care for them continually. An additional 1 million to 5 million have mild or moderate dementia. Ten times as many people are affected now as were at the turn of the century. The number of people with severe dementia is expected to increase 60 percent by the year 2000. Unless cures or means of prevention are found for the common causes of dementia, 7.4 million Americans will be affected by the year 2040—five times as many as today (see figure 1). The middle line on figure 1 assumes no change over time in the probability of developing severe dementia at a given age, and it does not hinge on new births but rather projects cases of dementia based on those already born. Further increases in life expectancy would increase the number of cases expected, and finding means to prevent dementing disorders would lower it.

The public has only recently become aware of the problems posed by dementing illnesses. Dementia and Alzheimer's disease (AD) have become household words only in the last few years. Efforts of national organizations, such as the Alzheimer's Disease and Related Disorders Association (ADRDA), have emphasized the plight of families and publicized the problems faced by nationally famous individuals who have developed dementia (e.g., Rita Hayworth). The most prevalent disorder causing dementia, Alzheimer's disease, has risen from relative obscurity to the cover of *Newsweek* magazine, the pages of *Life*, and prime-time television ("Do You Remember Love?" a made-for-television movie aired by CBS in May 1985). One book on caring for patients with dementia, *The 36-Hour Day*, has sold over 500,000 copies, and several other books for the general public have found sizable audiences.

Interest among health and social service professionals has risen in parallel with public awareness. Medical attention to Alzheimer's disease began to increase in the 1970s, catalyzed in 1976 by an editorial in a medical journal calling attention to the high prevalence and perniciousness of the disease and by activities supported by various Federal research institutes (the National Institute on Aging, the National Institute on Neurological and Communicative Disorders and Stroke, and the National Institute of Mental Health). Dozens of professional books, special issues of professional journals, and symposia proceedings on problems related to dementia have appeared since then. Two new journals—the *American Journal of Alzheimer's*

Figure 1.—Current and Projected Cases of Severe Dementia in the United States, 1980-2040



SOURCE: P.S. Cross and G.J. Gurland, "The Epidemiology of Dementing Disorders," contract report prepared for the Office of Technology Assessment, 1986.

Care, for caregivers, and *Alzheimer's Disease and Associated Disorders: An International Journal*, for scientists and clinical investigators—deal specifically with this topic.

Professional recognition of the problems posed by dementia is also reflected in (and partly caused by) increased funding for biomedical research and training. Federally funded research on dementing conditions has increased from $3.9 million in 1976 to an estimated $67 million in 1987. Federal funding has been supplemented by support from nongovernment organizations and foundations such as ADRDA, the American Federation for Aging Research, and the John Douglas French Foundation on Alzheimer's Disease.

Most recently, policymakers have become concerned with problems related to dementia because of the substantial costs of dealing with the dis-

The ultimate solution for the problem of dementia would be a "technical fix." There is no assurance that such a solution is possible at all, and it is certainly not likely in the next several years.

eases, and the relatively poor financial coverage of long-term care services needed by individuals with dementia and their families.

GOALS OF PUBLIC POLICY RELATED TO DEMENTIA

Consensus on the goals of public policy related to dementia is necessary as a background for policy change. Policy goals presuppose a set of accepted premises. One such premise is that individuals with dementia should be accorded the same respect for their person that they could have expected if they had not lost mental abilities. This does not imply, however, that the same decisions will always be reached—decisions to forgo life-sustaining treatment, for example, may be more acceptable in the presence of irreversible dementia than without it.

Another common assumption is that the family has the best interests of a dependent person with dementia in mind, and the best available information about what the patient would have wished. This is not always the case, but it is a starting point for many medical, financial, and legal decisions, and puts the burden of proof on those who believe that the assumption is unwarranted in a particular case. A final assumption is that the government has some role in protecting the rights and health of an individual with dementia, although the proper degree of government involvement in financing, coordinating, and directly providing services is subject to debate.

The degree to which funds should be transferred from one generation to another is an underlying unresolved issue in many public policies. Transfers within families are generally left to the individuals involved, but many government programs either directly transfer funds from one group to another (e.g., Social Security and Medicare for older Americans, and education and recreation subsidies for the young) or attempt to enforce familial responsibilities in public programs (e.g., requiring spouses to pay expenses incurred under Medicaid). The care of dependent adults has been a traditional concern, but the aging of the population has brought out the uncertainties and lack of consensus much more forcefully in recent decades, and public policies reflect these tensions.

Overall policy goals can be roughly categorized into two groups: those intended to diminish the magnitude of the problem for future generations, and those directed at ameliorating problems already facing patients with dementia and those who care for them, which are relevant now and in the next few years. The long-term goals include searching for ways to elim-

inate the diseases causing dementia, or at least to diminish their severity and consequences. The ultimate solution for the problem of dementia would be a "technical fix"—a fully effective way to prevent all dementing diseases, or a drug or surgical procedure to reverse their symptoms. There is no assurance that such a solution is possible at all, and it is certainly not likely in the next several years. That does not detract from the long-term practical benefits of supporting research, but it does suggest that it would be unwise to rely exclusively on the hope of a cure for all the diseases. A balanced policy will ensure support for research combined with efforts to address existing problems—to deal with those who now have dementia or will develop it before there are technical means to prevent or eradicate it.

Near-term goals include training caregivers (family, volunteer, and professional), improving care practices in acute and long-term care, and devising means to pay for the catastrophic expenses brought on by dementing illness. Some policies can influence both immediate and long-term goals. Research on clinical care and service delivery, for example, can both improve current practice and assist future generations. Education raises general awareness and also improves the prospects for finding an ultimate solution.

Several general short-term goals are repeatedly stressed in the literature dealing with the care of persons with dementia, although they are rarely stated explicitly. Some of these objectives are:

- to preserve maximum independence of the affected individual;
- to provide a continuum of care—a full range of services available at different stages of illness and adaptable to changes in the individual's family, finances, and needs;
- to efficiently coordinate the provision of care to maximize the match between available services and the needs and preferences of the individual and the family;
- to preserve the dignity of the affected individual;
- to reduce the severity of symptoms;
- to treat medical problems that may worsen dementia or cause pain and suffering;
- to cultivate preserved abilities and reduce the adverse effects of lost abilities;
- to foster the integrity of the family and minimize family stress; and
- to distribute the catastrophic costs of caring for those with dementia across the population without encouraging overuse of publicly financed services.

Attaining these goals may not be possible in many cases, and consensus on how best to achieve them has proved elusive. The role of government in assuring quality and paying for long-term care, for example, is the subject of extensive debate, and current policies reflect this lack of consensus.

FEDERAL POLICY PRIORITIES

The Federal Government can influence the problems posed by disorders causing dementia in hundreds of ways, many of which are described in this report. Federal policy options range from direct intervention to indirect

encouragement of others to act. The Federal Government can catalyze actions by State or local governments, citizens' groups, or private organizations (e.g., by disseminating information about dementia, services, or methods of caring for patients). In other areas, the Federal Government has a more direct or exclusive role (e.g., support for biomedical research). The ways in which the issues arising from dementing illness are addressed will be subject to political and technical debate, but the *objectives* of public policy are likely to revolve around these priorities:

- support for biomedical research,
- support for health services research,
- education,
- financing long-term care,
- patient assessment and coordination of services,
- increasing the range of services available, and
- assuring quality care.

Several of the priority areas overlap, and policies that affect one will necessarily have an impact on the others. Programs to educate consumers would, for example, depend on biomedical and health services for reliable information. Educated consumers would, in turn, be in a better position to assure quality care, obtain financing through existing mechanisms, plan their own finances prudently, and become knowledgeable about available services. Policies affecting financing would influence all other aspects of care because payment methods often determine the range of services made available; many observers believe, therefore, that policy change should focus first on financing. Yet no service system can work without all the pieces in place, including available trained personnel and mechanisms for coordinating services and assessing needs (whether formally or informally).

Policy changes on one front will thus need to be assessed for their overall impact. A balanced approach, with greatest efforts centering on those areas for which the Federal Government is most responsible, is most likely to lead to improved care.

REASONS FOR INCREASED INTEREST IN DEMENTIA

The new awareness of dementia can be traced to several sources, including the aging of the population, changing medical practices, and the activities of lay organizations.

Life expectancy at birth has risen from 47.3 years in 1900 to 74.5 years in 1982. More than four of every five Americans born this year can expect to reach age 65, compared with two of every five in 1900. The oldest groups are expanding most rapidly. The prevalence of severe dementia rises from approximately 1 percent (ages 65 to 74), to 7 percent (ages 75 to 84), to 25 percent (over age 85). The aging of the population, particularly the rising numbers of those over 85, thus results in many more cases of dementia. Longevity among those over age 65 has also increased dramatically in the last decade, adding further to the number of people at risk of developing dementia. These population trends partly explain the greater public awareness of dementia.

As physicians and other health professionals see more elderly patients, medical problems associated with aging receive more attention. The creation of the National Institute on Aging in 1974 (Public Law 96-296) resulted in part from greater awareness about aging. But diagnostic classifications have also changed radically. For example, the standard classification system used now for dementia—the *Diagnostic and Statistical Manual* of the American Psychiatric Association, 3rd edition (DSM-III)—was published in 1980. Diagnostic labeling has changed as well. In the past, neurologists and psychiatrists commonly labeled dementia beginning before age 65 as presenile dementia or Alzheimer's disease. Those whose symptoms appeared after age 65 were said to have senile dementia. This distinction has largely been eliminated, with both groups of patients categorized as having Alzheimer's disease or dementia of the Alzheimer type.

New terminology and shifting theories of causation have unified a large number of disorders under the term dementia. Until recently, many physicians believed that dementia was usually caused by atherosclerosis (a common disease of the blood vessels, often called "hardening of the arteries"). Many patients were said to have "cerebral arteriosclerosis" (a particular form of atherosclerosis) based on insufficient evidence. (This is still a common diagnosis in many nursing homes, reflecting outmoded diagnostic practices among referring physicians.) Work done in the United States and Europe from the late 1950s to the present, however, has found that the most common type of dementia is Alzheimer's disease (66 percent according to aggregate data from several studies). Several forms of dementia *are* due to vascular disease, and as a group they constitute the second most common cause of dementia. Vascular diseases causing dementia also have been differentiated and more specifically classified.

Many public organizations have formed around issues related to dementing conditions. ADRDA, for example, was created in June 1979 by several family support groups that had sprung up independently throughout the country. It has since become the largest national organization focused on dementia and the needs of caregivers. ADRDA has also played an important role in attracting media attention to the problems faced by families. There are many other national foundations—the John Douglas French Foundation and national organizations concerned with Huntington's disease, Parkinson's disease, multiple sclerosis, head injury, stroke, and other brain impairments that cause dementia. Some organizations deal with specific diseases while others, such as the Family Survival Project in California, focus on issues common to brain impairment in adults caused by a multitude of diseases. Such nongovernment organizations have helped raise public awareness of the severe problems posed by dementia.

Policymakers have also become more interested in dementia, because their constituents express concern and because many problems stemming from dementia affect and are affected by government activities. Finally, the economic costs of dementing illness have caused concern to those who must pay for the care of a loved one and to government administrators and legislators concerned about spending, particularly for long-term care. Individuals with dementia constitute perhaps the largest definable population group

Although the diseases causing dementia are generally not reversible, they are treatable. Treatment for most cases centers on minimizing the effects of the illness rather than attempting to return to normal mental function.

of those who require long-term care for extended periods, and payments for long-term care under the Medicaid program account for up to 10 percent of some State budgets.

POLICY INTEREST IN DEMENTIA

Growing congressional interest in Alzheimer's disease is reflected in the number of bills that specifically mention the condition—three bills (having to do with designation of National Alzheimer's Week) in the 97th Congress (1981 to 1982), and 26 in the 98th Congress (1983 to 1984). Several called attention to the problem by designating November as Alzheimer's Disease Month, while others dealt with health care and biomedical research. During the 98th Congress, five Alzheimer's disease research centers were established by the National Institutes on Aging. In the 99th Congress (1985 to 1986), 38 bills were introduced. The major health care issues for patients with dementia have been more directly addressed than in previous Congresses. Another five research centers have been created, a prototype Alzheimer's disease registry will soon be started, and several demonstration projects to deliver respite care will be funded.

Federal executive agencies have also shown increased awareness of the problems caused by dementia. Most health and social service programs relating to this issue are administered by the U.S. Department of Health and Human Services (DHHS). In 1981, Margaret Heckler created a Task Force on Alzheimer's Disease as her first act upon confirmation as Secretary of HHS. The Task Force issued a report in 1984, and continues to function under the current Secretary, Otis Bowen. In one article, then-Secretary Heckler noted:

> The cost of AD is very high. Many Alzheimer's patients are maintained in family homes. The total cost for nursing homes alone is estimated at over $13 billion per year; by 1990 that figure could exceed $41 billion. But the financial cost is in many ways secondary to the real toll that Alzheimer's exacts. This disease robs society of the contribution of productive individuals with a wealth of accumulated wisdom and life experience. It also pulls into its eddy friends and family members who give up their own pursuits to look after their afflicted loved ones.

The Veterans Administration (VA), military health services, and Indian Health Service are also concerned with dementia, because these agencies deliver health and social services to eligible populations, either directly or

under contract to other providers. State governments have shown interest in the problems of dementia as well. At least 21 States have major legislative initiatives, including over 80 bills on Alzheimer's disease (at least 20 of which became State laws in 1985 and 1986). Several others have made administrative changes in the absence of new legislation. Some States (e.g., California, Maryland, Kansas, Texas, Minnesota, Rhode Island, and Illinois) have developed carefully planned and widely publicized approaches to problems of dementia.

WHAT IS DEMENTIA?

Dementia is a complex of symptoms that can be caused by many different underlying diseases. The process of classifying dementia requires that symptoms be identified and carefully assessed before the underlying disease or condition causing the dementia is diagnosed.

Symptoms of Dementia

Although loss of recent memory is its hallmark, the term dementia implies global impairment of mental functions. The symptoms can include loss of language functions, inability to think abstractly, inability to care for oneself, personality change, emotional instability, and loss of a sense of time or place.

Dementia is different from mental retardation because it indicates a *loss* of previous abilities. (Those with mental retardation have below average mental ability rather than a loss of previous capabilities; they can also develop dementia if their abilities decline further.)

Dementia differs from *delirium* because delirium is associated with diminished attention or temporary confusion. Delirium implies a transient loss of mental abilities, as during intoxication or following acute head injury. It is not always easy to distinguish dementia from retardation or delirium, particularly among the very old or those about whom there is little available medical information. But differences are usually clear, and diagnostic classification relies on maintaining the distinctions.

Disorders Causing Dementia

More than 70 conditions can cause dementia. Identifying the symptoms leads to a search for the cause—the process of diagnosis. The disorders covered in this report (see table 1) can be classified into several groups. Degenerative disorders are diseases whose progression cannot be arrested. The ultimate cause of most such diseases is not known, and these disorders cause progressive deterioration of mental and neurological functions, often over years. Alzheimer's disease is by far the most prevalent degenerative dementia, found in 66 percent of all cases. The remaining disorders in table 1 are listed by cause. A few of them can be reversed following treatment, but truly reversible dementia occurs in only 2 to 3 percent of cases. In most cases, dementia is stable or progressive (although the severity can often be reduced by treating other medical problems that exacerbate the symptoms). Although the diseases causing dementia are generally not reversi-

Table 1.—Disorders Causing or Simulating Dementia

Disorders causing dementia:
Degenerative diseases:
- Alzheimer's disease
- Pick's disease
- Huntington's disease
- Progressive supranuclear palsy
- Parkinson's disease (not all cases)
- Cerebellar degenerations
- Amyotrophic lateral sclerosis (ALS) (not all cases)
- Parkinson-ALS-dementia complex of Guam and other island areas
- Rare genetic and metabolic diseases (Hallervorden-Spatz, Kufs', Wilson's, late-onset metachromatic leukodystrophy, adrenoleukodystrophy)

Vascular dementia:
- Multi-infarct dementia
- Cortical micro-infarcts
- Lacunar dementia (larger infarcts)
- Binswanger disease
- Cerebral embolic disease (fat, air, thrombus fragments)

Anoxic dementia:
- Cardiac arrest
- Cardiac failure (severe)
- Carbon monoxide

Traumatic dementia:
- Dementia pugilistica (boxer's dementia)
- Head injuries (open or closed)

Infectious dementia:
- Acquired immune deficiency syndrome (AIDS)
  - AIDS dementia
  - Opportunistic infections
- Creutzfeldt-Jakob disease (subacute spongiform encephalopathy)
- Progressive multifocal leukoencephalopathy
- Post-encephalitic dementia
- Behcet's syndrome
- Herpes encephalitis
- Fungal meningitis or encephalitis
- Bacterial meningitis or encephalitis
- Parasitic encephalitis
- Brain abscess
- Neurosyphilis (general paresis)

Normal pressure hydrocephalus (communicating hydrocephalus of adults)

Space-occupying lesions:
- Chronic or acute subdural hematoma
- Primary brain tumor
- Metastatic tumors (carcinoma, leukemia, lymphoma, sarcoma)

Multiple sclerosis (some cases)

Auto-immune disorders:
- Disseminated lupus erythematosis
- Vasculitis

Toxic dementia:
- Alcoholic dementia
- Metallic dementia (e.g., lead, mercury, arsenic, manganese)
- Organic poisons (e.g., solvents, some insecticides)

Other disorders:
- Epilepsy (some cases)
- Post-traumatic stress disorder (concentration camp syndrome—some cases)
- Whipple disease (some cases)
- Heat stroke

Disorders that can simulate dementia:
Psychiatric disorders:
- Depression
- Anxiety
- Psychosis
- Sensory deprivation

Drugs:
- Sedatives

Table 1.—Disorders Causing or Simulating Dementia—Continued

- Hypnotics
- Anti-anxiety agents
- Anti-depressants
- Anti-arrhythmics
- Anti-hypertensives
- Anti-convulsants
- Anti-psychotics
- Digitalis and derivatives
- Drugs with anti-cholinergic side effects
- Others (mechanism unknown)

Nutritional disorders:
- Pellagra (B-6 deficiency)
- Thiamine deficiency (Wernicke-Korsakoff syndrome)
- Cobalamin deficiency (B-12) or pernicious anemia
- Folate deficiency
- Marchiafava-Bignami disease

Metabolic disorders (usually cause delirium, but can be difficult to differentiate from dementia):
- Hyper- and hypo-thyroidism (thyroid hormones)
- Hypercalcemia (calcium)
- Hyper- and hypo-natremia (sodium)
- Hypoglycemia (glucose)
- Hyperlipidemia (lipids)
- Hypercapnia (carbon dioxide)
- Kidney failure
- Liver failure
- Cushing syndrome
- Addison's disease
- Hypopituitarism
- Remote effect of carcinoma

SOURCE: Adapted from R. Katzman, B. Lasker, and N. Bernstein, "Accuracy of Diagnosis and Consequences of Misdiagnosis of Disorders Causing Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986.

ble, they are treatable. Treatment for most cases centers on minimizing the effects of the illness rather than attempting to return to normal mental function.

Alzheimer's disease is marked by distinctive changes and loss of nerve cells that can be detected microscopically in brain tissue. The term may actually refer to a *group* of diseases with possibly different causes and perhaps distinguished by their symptoms, rate of progression, inheritance patterns, and age at onset. These are grouped under one term because scientific understanding has not progressed sufficiently to distinguish them.

Dementia caused by disease of the blood vessels (vascular dementia) accounts for the second largest number of cases in most studies, although the interpretation of such studies is being reevaluated to ascertain the degree to which vascular disease itself can cause dementia. It is clear, however, that vascular disease may worsen the symptoms of dementia.

Some cases of dementia can be prevented: Toxic dementias and those caused by infections are clear examples. Once the brain is structurally damaged, however, dementia from these causes is usually permanent.

Disorders that can simulate dementia, in contrast, include conditions for which treatment may eliminate dementia. Treatment of these can be instituted *in order to* restore mental function. Dementia will not invariably dis-

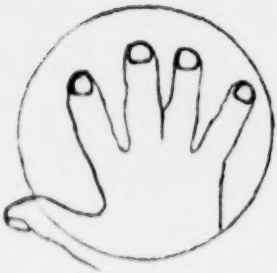


Photo credit: Office of Technology Assessment

S (upper left) goes to the Family Respite Center in northern Virginia for day care (lower left). He is a graphic artist who now has Alzheimer's disease. When asked to draw the hand pictured at bottom right, he draws the picture seen in the upper right. S's drawing is smaller than the model and shows distortion of spacial relationships, incorrect counting of fingers, and misplacement of fingernails. Such errors are typical of those due to damage to the brain caused by Alzheimer's disease.

appear with treatment, but it is more likely to do so than for diseases in the other categories. The difference between these diseases and the first category of disorders is the rapidity of improvement and the higher likelihood of complete recovery of mental functions.

There is substantial overlap in the categories. Many older people suffering from depression, for example, show signs of dementia. Some reports have found that as many as 31 percent of those thought to have dementia have depression instead. Yet the rate of misdiagnosis is not as high today, because physicians have become more sophisticated in separating the various types of dementia and differentiating this condition from other mental symptom complexes. Those thought to be "misclassified" as depressed have been studied years later and found to be at much higher risk of eventually developing obvious dementia—suggesting they had an underlying dementia at the time of "misclassification". One author notes the continuum from normal mental function to severe dementia including intermediate points such as "forgetfulness," "at risk of dementia," and various severities of clinical dementia. The overlap between disorders that cause dementia and those

that simulate it cannot always be clearly defined with current medical knowledge, and it is sometimes difficult to pinpoint where individuals are on the continuum of mental capacity. Scientific discoveries might shift any one of the degenerative disorders into another category if a cause were found or a treatment discovered that could halt the loss of brain cells. The categories suggested in table 1 are intended to clarify and highlight conceptual distinctions rather than to imply that diseases fall neatly into separate categories.

The distinctions among disease categories are nonetheless important for several reasons. Those with Alzheimer's disease (with or without other conditions) constitute a large portion of patients with dementia. At present there is no cure, and treatment focuses on changing the environment and adapting caregiver behavior to meet the needs of patients, rather than on curing the dementia through medication or surgery. Making the specific diagnosis of Alzheimer's disease precludes certain types of therapy, and also highlights the need to begin training caregivers about what to expect and how to deal with the expected worsening dementia. Diagnosis is therefore important in informing families about what to expect, but it is not sufficient to determine care needs without also assessing family support, severity of the disease, and the individual patient's symptoms. Decisions about medical care, social services, and family expectations all hinge on accurate diagnosis. The diagnosis of dementing illnesses will be the topic of a consensus development conference at the National Institutes of Health July 6-8, 1987.

Public policy priorities differ for those whose dementia can be eliminated. The paramount need of such patients is for accurate diagnosis and appropriate treatment, both of which are aspects of acute medical or mental health care. Public policies to identify these patients can reduce the number misdiagnosed with "irreversible" dementia and wrongly channeled into long-term care. The number of individuals with dementia whose symptoms can be treated and eliminated is estimated at 2 to 3 percent, and the costs of unnecessarily providing long-term care for them are likely to offset the costs of diagnosis for all cases of dementia. Policy issues related to disorders causing progressive dementia, on the other hand, center on appropriate long-term care for those already affected, and on research to identify new treatments or means of prevention.

A different way to classify disorders causing dementia is found in the International Classification of Diseases (see table 2). That system, called ICD-9, is used to code diagnoses in most hospitals and clinics, and is the starting point for diagnosis-related group reimbursement under Medicare. The classification is well adapted for many specific disorders. No specific code exists for several disorders, however, and a large number of diagnostic categories that include many persons with dementia (e.g., someone with Parkinson's disease) do not separate individuals with dementia from those without it. Many diseases listed in table 1 do not have ICD-9 codes, and

Table 2.—ICD-9 Codes for Disorders Causing Dementia

094	**Neurosyphilis**
094.1	**General paresis**
290	**Senile and presenile organic psychotic conditions**
290.0	Senile dementia, simple type
290.1	Presenile dementia
290.2	Senile dementia, depressed or paranoid type
290.3	Senile dementia with acute confusional state
290.4	Arteriosclerotic dementia
291	**Alcoholic psychoses**
291.1	Korsakov's psychosis, alcoholic
291.2	Other alcoholic dementia
294	**Other organic psychotic conditions (chronic)**
294.0	Korsakov's psychosis, nonalcoholic
294.1	Dementia in conditions classified elsewhere
294.8	Other chronic organic psychotic conditions
294.9	Unspecified chronic organic psychotic conditions
310	**Specific nonpsychotic mental disorders following organic brain damage**
310.1	Nonpsychotic cognitive or personality change following organic brain damage
310.9	Unspecified nonpsychotic mental disorders following organic brain damage
331	**Other cerebral degenerations**
331.0	Alzheimer's disease
331.1	Pick's disease
331.2	Senile degeneration of the brain
331.3	Communicating hydrocephalus
331.5	Creutzfeldt-Jakob disease
331.6	Progressive multifocal leukoencephalopathy
331.7	Cerebral degeneration in other disease elsewhere classified
331.8	Other cerebral degeneration
331.9	Unspecified cerebral degeneration
333	**Other extrapyramidal disease and abnormal movement disorders**
333.4	Huntington's chorea
437	**Other and ill-defined cerebrovascular disease**
437.0	Cerebral atherosclerosis
437.1	Other generalized ischemic cerebrovascular disease
437.2	Hypertensive encephalopathy
797	**Senility without mention of psychosis**
Any patients have dementia, but category also includes some without dementia:	
279	**Disorders involving the immune mechanism**
279.19	Acquired immune deficiency syndrome (AIDS dementia)
290	**Senile and presenile organic psychotic conditions**
290.8	Other senile/presenile organic psychotic conditions
290.9	Unspecified senile/presenile organic psychotic conditions
323	**Encephalitis, myelitis and encephalomyelitis**
323.0	Kuru
323.1	Subacute sclerosing panencephalitis
323.2	Poliomyelitis
323.3	Arthropod-borne viral encephalitis
323.4	Other encephalitis due to infection
323.5	Encephalitis following immunization procedures
323.6	Postinfectious encephalitis
323.7	Toxic encephalitis
323.8	Other
323.9	Unspecified cause
332	**Parkinson's disease**
333	**Other extrapyramidal disease and abnormal movement disorders**
333.0	Other degenerative disease of the basal ganglia
438	**Late effects of cerebrovascular disease**

SOURCE: *International Classification of Diseases*, 9th Revision Conference, 1975 (Geneva: World Health Organization), vol. 1, 1977 and vol. 2, 1978, modified by *Coding Clinics for ICD-9 CM*, American Hospital Association, various issues.

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individuals with them would be classified in nonspecific categories. These shortcomings limit the usefulness of ICD-9 in refining epidemiologic studies because it is impossible to specify only those persons who have dementia.

The State of California recently reviewed the various systems of nomenclature for dementing disorders. The analysts suggested grouping disorders under a new broad category "acquired cognitive impairment," according to the subcategories noted in table 3. The confusion over terminology may

Table 3.—California State Listing of Acquired Cognitive Impairments

- *Primary (cortical) degenerative dementias—DSM-III:*
  - Alzheimer's disease
  - Pick's disease
- *Degenerative dementias with involvement of motor systems:*
  - Amyotrophic lateral sclerosis
  - Cerebellar degenerations
  - Guam-Parkinson-dementia complex
  - Huntington's disease
  - Parkinson's disease
  - Progressive supranuclear palsy
  - Other rare disorders: including Hallervorden-Spatz disease, Kufs' disease, Wilson's disease, metachromatic leukodystrophy, adrenoleukodystrophy
- *Vascular:*
  - Binswanger disease
  - Cerebrovascular accident: including hemorrhage, stroke, aneurysms (recent and past)
  - Cortical microinfarcts
  - Lacunar infarctions
  - Multi-infarct dementia
- *Postanoxia or postischemia—due to:*
  - Carbon monoxide
  - Cardiac arrest
  - Strangulation, asphyxiation, or suffocation
- *Traumatic:*
  - Intracranial injury without skull fracture: open and closed
  - Intracranial injury with skull fracture: open and closed
  - Fat embolism
  - Post-traumatic brain syndrome: nonpsychotic psychotic
- *Auto-immune:*
  - Disseminated lupus
  - Multiple sclerosis
  - Primary CNS vasculitis
- *Central nervous system infections:*
  - AIDS (primary or opportunistic infections)
  - Behcet syndrome
  - Creutzfeldt-Jakob disease
  - Encephalitis, herpes simplex
  - Fungal, parasitic, and chronic bacterial meningitis, abscesses, and granuloma
  - Neurosyphilis
  - Postencephalitic dementia
  - Progressive multifocal leukoencephalopathy
- *Hydrocephalus, adult onset* (normal pressure)
- *Space-occupying lesions:*
  - Hematomas: including subdural, epidural, and intracerebral
  - Metastatic carcinoma, lymphoma, leukemia
  - Primary brain tumors
- *Toxic dementias:*
  - Alcoholic dementia
  - Drugs: including neuroleptics, diazepam-related hypnotics, anticonvulsants, beta blockers, digitalis
  - Korsakoff's syndrome
  - Metallic poisons: including lead, mercury, arsenic, manganese
  - Organic poisons: including solvents, organophosphates
- *Psychiatric illness presenting as dementia:*
  - Chronic schizophrenia
  - Conversion disorder
  - Depression
  - Ganzer's syndrome
  - Paranoia
- *Nutritional disorders:*
  - Marchiafava-Bignami disease
  - Pellagra
  - Thiamine deficiency (Wernicke-Korsakoff syndrome)
  - Vitamin B-12 or folate deficiency
- *Metabolic disorders:*
  - Addison disease
  - Cushing syndrome
  - Hepatic failure
  - Hypercalcemia
  - Hypercapnia
  - Hyperlipidemia
  - Hypoglycemia
  - Hypo- and hyperthyroidism
  - Hypopituitarism
  - Hypo- and hypernatremia
  - Remote effects of carcinoma
  - Uremia
- Sensory deprivation (agnosia)
- Other disorders:
  - Concentration camp syndrome
  - Epilepsy
  - Heat stroke
  - Whipple disease

SOURCE: D.A. Lindeman, N.G. Bliwise, G. Berkowitz, et al., "Development of a Uniform Comprehensive Nomenclature and Data Collection Protocol for Brain Disorders," Institute for Health and Aging, University of California, San Francisco, June 1986.

The focus of most medical management is family education—training caregivers to adapt to the patient, simplifying the individual's living space, and referring relatives to family support services.

be reduced if revisions of the two most widely used diagnostic classifications are made compatible. Revision of the ICD-9, to be called ICD-10, is scheduled for 1989. DSM-III is a set of guidelines for making diagnosis of mental disorders. It is the most widely used classification for the symptoms of dementia, and its criteria have been used in most recent studies. The revision of DSM-III will be called DSM-IV and will likely be made available after release of ICD-10. The two classifications are promised to be more compatible than DSM-III and ICD-9.

COURSE OF THE ILLNESSES

The course of a dementing illness varies from one person to another as well as among the different disorders. A few generalizations can be made, however, about progressive dementing illnesses. Onset is usually noticed by the person with the disorder, family members, friends, or colleagues at work (rather than by a physician). Although some disorders appear suddenly, most—including Alzheimer's disease—are insidious. People lose some mental ability, usually memory, or begin to show poor judgment or incompetence at work. They often succeed in hiding their symptoms for months or even years (if symptoms are mild), but the disability eventually becomes serious enough to merit medical investigation.

A physician is typically consulted by the individual or family, initiating the diagnostic process. If the indvidual is seen early by a physician knowledgeable about dementia, the first visit will result in the scheduling of appropriate tests or referral to another specialist (usually a neurologist or psychiatrist) who will direct and monitor the use of diagnostic tests. An estimated 80 percent accuracy in diagnosis can be obtained through medical history and physical examination, while 90 percent accuracy can be achieved when these are supplemented by a battery of psychological and laboratory tests and by radiological examinations.

Once diagnosis is completed, treatment can be started for some dementing conditions (and any other medical conditions detected during diagnostic evaluation). Medications may assist in managing some symptoms, the progression of which can be slowed or arrested in a few cases. The focus of most medical management, however, is family education—training caregivers to adapt to the patient, simplifying the individual's living space, and referring relatives to family support services. Current medical management of dementia is based largely on anecdotal reports and clinical impressions rather than on solid data, since there have been relatively few clinical investigations. Drug treatment to improve intellectual function and memory

has been a topic of intense investigation, but results have not yet shown clinically significant improvement. Drug management of behavioral disorders can benefit patients and ease the burden for caregivers, but it must be carefully planned and monitored.

Diagnosis and treatment can continue for several years. Repeated visits for evaluation may be necessary to establish a final diagnosis—particularly for cases of early dementia, unusual progression, or atypical symptoms. Treatment, including medication, may be changed from time to time in response to changing needs or adverse drug effects.

An individual with dementia also often requires intermittent medical care for other illnesses. Because dementia is most prevalent among the very old, and because the very old are at risk of multiple medical disabilities, it is common for those with dementia to require attention for diseases of the heart, lungs, kidneys, or other organs. Their mental incapacity also places them at increased risk of falls, mistakes in medication, and household accidents. Individuals with dementia frequently need dental care. Those with dentures often lose them or break them; those with other dental problems may not become aware of them until they have become serious or caused undue pain.

Most dementing conditions last years, often decades. One recent study found the average duration of illness, from first onset of symptoms to death, was 8.1 years for Alzheimer's disease and 6.7 years for multi-infarct dementia. The time from *diagnosis* to death averaged 3.4 years for Alzheimer's disease and 2.6 years for multi-infarct dementia, suggesting that patients typically show symptoms for over 4 years before a diagnosis is made. Recent improvements in professional education and increased public awareness may eventually shorten this period. The duration of a dementing illness is unpredictable, however—Alzheimer's disease can last up to 25 years.

Patients with dementia generally die of some other illness, and dementia is associated with increased overall mortality. Alzheimer's disease is often cited as the fourth leading cause of death in the United States (although not reflected on death certificates or in official statistics). Such statements assume that each year the number of new cases roughly equals the number of deaths of those with Alzheimer's disease, and that shortened life expectancy is related to the presence of Alzheimer's disease—both untested assumptions. *Mortality* caused by dementing conditions is, in any case, not the only consideration; of equal or greater concern are deterioration of valued human mental capacities, loss of autonomy, and catastrophic expenses caused by the ensuing need for long-term care.

Long-term care refers to medical, mental health, and personal services rendered to those with diminished capacity for self-care due to illness. Brain damage caused by a disease process results in loss of mental functions and dependency on others. Long-term care is often needed from the beginning of the disease, and can precede diagnosis. Individuals' needs differ markedly. Some remain at home throughout the illness, while others benefit from day care or nursing home placement soon after symptoms are noted. Recent research has shown that the use of formal services is, in fact, more

Mortality is not the only consideration; of equal or greater concern are deterioration of mental capacities, loss of autonomy, and catastrophic expenses caused by the need for long-term care.

strongly correlated with characteristics affecting the person most responsible for taking care of someone with dementia than with severity of symptoms or other characteristics of the ill individual. Yet there would be no dependency on a caregiver if not for the illness.

Since all individuals with dementia eventually become dependent (if their disease runs full course), they all require long-term care. Individuals typically need long-term care from onset to death, although the degree to which *formal* services are used varies. Most families keep someone with dementia at home for as long as possible, often despite extreme cost, health risk, and stress to themselves.

Two general hypotheses about long-term care for persons with dementia are important to public policy, but their validity has not been confirmed. One posits that care needs intensify as the disease worsens until the afflicted person dies. The other suggests that most of the caregiving burden is due to changes in behavior and personality. As the dementia worsens, behavioral problems diminish as the individual becomes weaker, less mobile, and eventually mute. If the second hypothesis were correct, the need for care would be greatest at midcourse of the illness, and services to support families through the worst periods might forestall institutional placement.

The complex interactions between the affected person's symptoms and stresses affecting the caregiver and family are equally important in predicting a need for formal long-term care services, but the crucial factors are only now being studied. The concept of a smooth progression of illness and dependency caused by it is illusory, with large variations in types of symptoms, rapidity and severity of progression of disease, and strength and resilience of informal supports.

Those with dementia generally die after years of being dependent on others for their care. The cause of death is usually a disease of a different organ system—pneumonia, heart disease, or kidney failure, for example. These individuals are logical candidates for hospice care in their last months, with an emphasis on allaying pain and suffering rather than prolonging life. Autopsy following death is often the only means of confirming what disease the person had, but the rate of autopsy in the United States has fallen dramatically, and an accurate diagnosis may never be ascertained. Failure to confirm a diagnosis at autopsy can interfere with accurate genetic counseling and analysis of the efficacy of medical care.

MAGNITUDE OF THE PROBLEM

The problems posed by disorders causing dementia will increase as the population ages and more people either develop a dementing disorder themselves or must care for a relative or friend. The magnitude of the problem can be gauged by projecting the number of people likely to be affected (the prevalence of dementia), estimating the costs of caring for those who now have dementia, and assessing some of the indirect burdens.

Prevalence of Dementia

Dementia can be divided into several categories by severity and type. Studies over the past several decades have varied widely in reported prevalence rates. These variations can be attributed to the different age groups studied, the inclusion or exclusion of people in long-term care facilities, degree of severity involved, methods of assessing mental function, or other sample characteristics. Most studies conducted since 1980 have followed DSM-III criteria, dramatically reducing the degree of variation from study to study.

Recent studies show a relatively narrow range of prevalence of severe dementia, from 5 to 7 percent of those over 65, with a median of 6.5 percent. Although the criteria for "severe" dementia vary from study to study, the degree of variation for this category is much less than if "mild" and "moderate" cases are also included. The extreme variation of results on mild and moderate cases makes projections of future prevalence impossible. Further, those with mild and moderate dementia in community studies are those about whom there is the greatest possibility of diagnostic error. For these reasons, projections of cases have been done only for severe dementia (see table 4). The total number of all cases can be estimated from these studies by assuming that for each case of severe dementia, probably at least one person and possibly up to three people have milder dementia and will eventually develop severe dementia if they live long enough.

Table 4.—Current and Projected Cases of Severe Dementia in the United States, 1980-2040 (thousand cases rounded to 2 significant figures)[a]

Age group	1980	2000	2020	2040
Under 65	78	88	150	150
65-74	160	180	300	290
75-84	550	860	1,000	1,700
Over 85	570	1,300	1,800	5,200
Total cases	1,400	2,400	3,300	7,300

[a]These projections are based on prevalence of severe dementia of 1 percent ages 65 to 74, 7 percent 75 to 84, and 25 percent 85 and over (Cross and Gurland, 1986). Cases under 65 have been estimated as follows: the 75,000 current cases (Mortimer and Hutton, 1985) under age 60 correspond to 48 percent of cases in the next oldest cohort (ages 65 to 74) (Cross and Gurland, 1986). Projections of future cases under 65 have been conservatively calculated as 50 percent of cases in the 65 to 74 cohort, for simplicity and to account partially for those aged 61 to 64. Another method would be to use the estimated 13.5 per 100,000 prevalence estimate among those 30 to 59 (Kokman, 1984, as cited in Mortimer and Hutton, 1975), but this is more complicated and more subject to error due to the shifting age structure within this very large age group. The table yields estimates of cases under age 65 at the conservative end of the range reported (5 to 10 percent of all cases—Cross and Gurland, 1986).

SOURCES: P.S. Cross and B.J. Gurland, "The Epidemiology of Dementing Disorders," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986.

Prevalence is most often reported as a percentage of people age 65 or older affected at a particular time. Average prevalence figures mask significant differences among different age groups. As noted earlier, the prevalence of severe dementia among those 65 to 74 is roughly 1 percent, compared with 25 percent for those over 84.

Some authors have used the terms "epidemic" and "rising pandemic" to describe the projected increase in prevalence of dementia. Use of such terms is subject to misinterpretation, however, because of their associations with uncontrolled infection. Although the number of people with dementia will rise substantially over the next several decades, it will not do so explosively. (One dementia, associated with acquired immune deficiency syndrome, is epidemic, but uncertainties about its prevalence, reversibility, and mortality preclude accurate projections.) Vascular dementia may drop in prevalence, paralleling the decline of stroke and hypertension. The prevalence of Alzheimer's disease, because it accounts for the largest number of cases, will largely determine the overall prevalence of dementia. Alzheimer's disease is expected to rise slowly in prevalence, in tandem with aging of the population.

Studies show general agreement on the overall prevalence of severe dementia among the population 65 or older, but substantial uncertainty exists about mild and moderate dementia, the oldest age group, ethnic and racial subgroups, nursing home populations, and subtypes of dementia. Some data, for example, suggest that the risk of developing dementia after age 84 begins to decline; other data do not support that hypothesis. That could be due to real decline, inadequate reporting (since dementia is "expected" in the very old and therefore not recorded), or insufficient sampling of the very old cohort. Many of these groups about which there is little information are among those expanding most rapidly (see figure 2). Policy planning will thus require rigorous investigation of prevalence rates among the very old, minority groups, and nursing home residents.

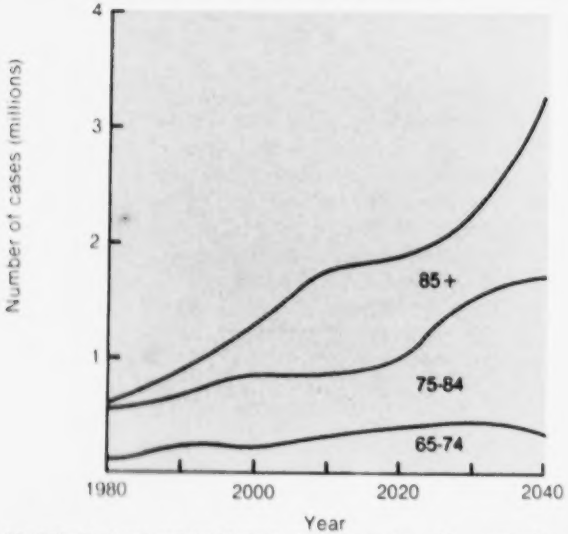
Costs of Dementia

Although the exact costs of dementing illness to the Nation cannot be calculated, all agree that they are already high and bound to rise at least in proportion to the expected increase in prevalence. The many studies of costs noted in this section do not provide estimates that are sufficiently accurate and reliable to permit refined policy planning, but they are a starting point for analysis of spending for different services. Policies that affect the largest spending categories (informal care and long-term care) are those accorded high priority by caregivers as well as those concerned about government spending.

Overall Costs

Two studies have attempted to estimate the overall costs to the Nation of caring for those with dementia. The National Institute on Aging (NIA) sponsored a study that estimated total costs of just over $38 billion in 1983. That study attempted to estimate only those costs exclusively due to dementia, but the projections (particularly those for the largest cost compo-

Figure 2.—Contribution of Elderly Age Groups to Projected Increase in Cases of Severe Dementia



SOURCE: P.S. Cross and G.J. Gurland, "The Epidemiology of Dementing Disorders," contract report prepared for the Office of Technology Assessment, 1986.

nents) were contingent on small pilot studies. A review of these cost estimates, prepared for the State of California, concluded that costs of dementia were large but could not be precisely defined. A Battelle Memorial Institute study commissioned by OTA estimated $24 billion to $48 billion total costs (projected to 1985). That study, too, tried to estimate only the costs specifically due to dementia, but it used different projection methods for estimating community and nursing home costs for long-term care. The estimates from these studies are similar in range, but they can be misinterpreted. Both the NIA and Battelle studies estimate costs of diagnosis, treatment, nursing home care, informal care, lost wages, and other indirect costs. Each component is large but cannot rigorously be projected, due to the paucity of relevant information, not study design.

In addition to studies of overall costs, some researchers have estimated costs related to dementia stemming from diagnosis, medical treatment, nursing home care, and informal long-term care; these are discussed below.

Costs of Diagnosis

The costs of diagnosis can be estimated by assuming that 200,000 new cases of severe dementia will occur each year, and that at least as many mild and moderate cases will come to the attention of physicians for diagnostic evaluation. The estimated incidence of 200,000 is calculated by assuming 1.5 million affected people and 7.5 year average duration, based on the average from one recent survey. That estimate is conservative, be-

Most families keep someone with dementia at home for as long as possible, often despite extreme cost, health risk, and stress.

cause it is based on figures at the low end of prevalence estimates, assumes only one diagnostic evaluation per case, and neglects those persons who are evaluated for dementia but are not found to have a dementing illness.

The cost of diagnosis per case depends on the number of times a patient must be seen (the patient may need periodic reevaluation if dementia is mild or presents atypically), local medical costs, and whether the diagnostic testing is done on an outpatient or inpatient basis (i.e., during repeated clinic visits or in the hospital). Outpatient diagnosis entails an estimated $1,000 to $2,000 for physician charges, laboratory tests, neuropsychological testing, brain imaging studies, and ancillary services. Costs for the laboratory tests alone can range from about $154 to about $1,110 per patient. Those figures suggest that it costs at least $400 million to $800 million each year nationwide to diagnose disorders causing dementia.

The Medicare program's costs for inpatient diagnosis differ according to geographic location, type of hospital, and discharge diagnosis. A hospital discharging a patient with the diagnosis of Alzheimer's disease would be reimbursed from $6,800 to $7,200 in most areas. If all cases were diagnosed following a single hospitalization, the national cost of diagnosis would be approximately $2.8 billion. Although no data show whether inpatient or outpatient diagnosis is more common, a survey of caregivers commissioned by OTA for this assessment did find that 30 percent of patients had never been hospitalized. Diagnosis in a hospital could have been done on a maximum of 70 percent, although the number is likely much lower because most hospitalizations would be for purposes other than initial diagnosis of dementia.

Hospital admission for diagnosis is not the norm in most centers; physicians who see many patients with dementia report that inpatient diagnosis is performed only for a small minority of patients. In fact, diagnosis as the sole reason for hospital admission would likely be disallowed for reimbursement under Medicare except in rural areas or special circumstances. Diagnosis is thus largely done on an outpatient basis, with attendant costs in the outpatient range rather than the much higher estimate for inpatient diagnosis.

Given all the uncertainties, a firm figure for cost of diagnosis cannot be stated. A reasonable estimate for the national cost of diagnosis would be $500 million to $1 billion each year—high, but relatively small compared with long-term care costs. The diagnostic process is more likely to be covered by Medicare and private health insurance than long-term care is, and therefore requires smaller out-of-pocket payment by patients.

Costs of Drugs and Medical Services After Diagnosis

Once a diagnosis is made, medical management of patients with dementia requires continued visits to physicians, drug treatment of behavioral symptoms and ancillary medical problems, mental health services, and intermittent hospital care for concurrent illnesses. One study estimated these medical costs due to dementia at just over $10 billion in 1983. Another study did not specify costs in dollars, but found that those with dementia were more likely to die during a hospital admission, had longer lengths of hospital stay, and were more likely to be discharged to a nursing home or require home assistance. The study also reported that:

> . . . Cognitive impairment at the time of admission may be regarded as a marker for sicker, less stable, more clinically complex patients. Such patients can be expected to fare worse than their mentally intact counterparts and to require more intense social service support if they survive to discharge.

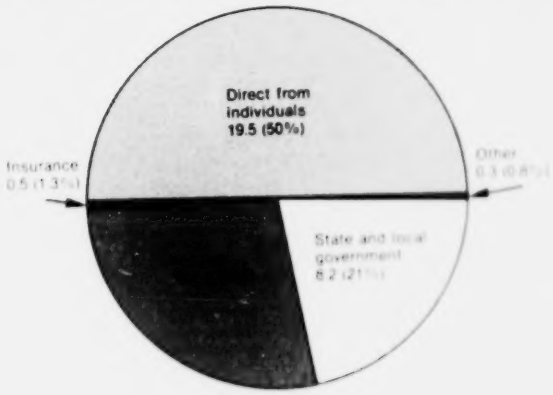
Costs of Nursing Home Care

In 1984, total national expenditures for nursing home care reached $32 billion; for 1986, the estimate is $38.9 billion. The 1986 estimate includes $19.5 billion from individuals (50 percent), $500 million from insurance (1.3 percent), $10.4 billion in Federal funds (27 percent), $8.2 billion in State and local payments (21 percent), and $300 million (0.8 percent) from other sources (see figure 3). Medicaid was the single largest payer for nursing homes. In 1980, Medicaid accounted for more than three-quarters of the total spent on long-term care under the six largest Federal programs (the other five are Medicare, Older Americans Act programs, State supplements to income, Title XX funds, and VA programs). Nursing home care is a small part of Medicare, and the services covered are restricted to short stays after hospitalization. Nursing home payments under Medicare were only $600 million of $64.6 billion total Medicare outlays in 1984, and accounted for 1.9 percent of the total spent nationwide on nursing home care.

Nursing home payments surged from 1.7 percent of all health care expenditures in 1950 to 5.8 percent in 1965, and then to an estimated 9.7 percent in 1986. Health care costs are significant, especially for older Americans (see figure 4). Among those over 64, fully 9.9 percent of their expenditures go for health care (compared with 2.6 percent for those under 25, and 5.4 percent for those 55 to 64). The difference is even more dramatic within the older age group. One study estimated out-of-pocket expenditures for health care and health insurance at 6.5 percent of income for those 65 to 69, compared with 13.7 percent for those 75 to 84, and 41.7 percent for those over 85.

The proportion of these expenditures directly caused by dementing illness is not known. The National Nursing Home Survey of 1977 found that 37 percent of nursing home residents had "chronic brain syndrome" or "senility" as noted by nursing home staff. Most people in these categories likely had what would now be called dementia, although some older adults with mental retardation might also have been misclassified as "chronic brain syndrome."

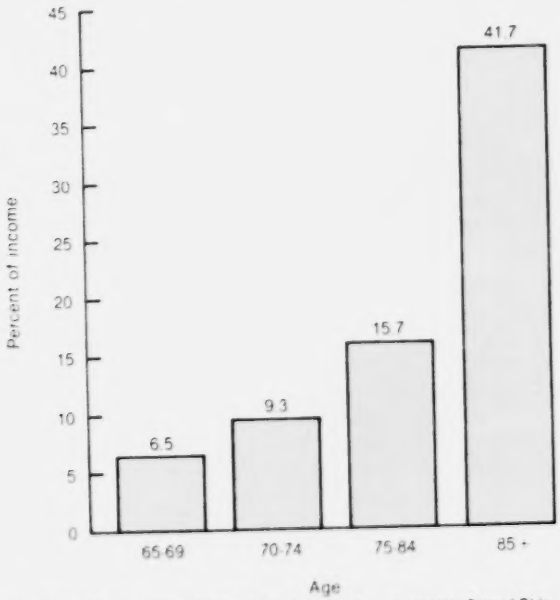
Figure 3.—1986 Estimated Costs of Nursing Home Care (billions of dollars)



Total = $38.9 billion

SOURCES: R.H. Arnett, D.R. McKusick, S.T. Sonnefeld, et al., "Projections of Health Care Spending to 1990," *Health Care Financing Review* 7 (3), spring 1986.

Figure 4.—Personal Payments for Health Care and Health Insurance



SOURCE: ICF, Inc., "The Role of Medicare in Financing the Health Care of Older Americans," submitted to American Association of Retired Persons, July 1985, table 21, adapted by the Office of Technology Assessment.

A recent sample of people admitted to nursing homes in Texas showed that 40 to 60 percent had diagnoses indicating dementia. A sample of 3,427 residents of 52 New York State nursing homes found 41 percent had diagnoses indicating dementia or extensively overlapping with it. Both samples used the admitting diagnosis (the accuracy of which depends on the quality of prior medical evaluation and varies widely from site to site) and are likely low for two reasons. First, dementia is commonly missed, especially in the very old, because it is "expected," even by many physicians. Second, physicians wishing to facilitate nursing home placement are often willing to list other diagnoses rather than dementia because nursing homes may be less willing to admit dementia patients.

Researchers at Johns Hopkins Medical School recently undertook the most reliable study to date, but it is small and preliminary. A research team performed thorough diagnostic investigations of 50 residents of a proprietary nursing home in Baltimore. The study found 39 (78 percent) had a dementing condition (an additional 7 residents had other mental diagnoses). More studies of nursing home populations that include rigorous diagnosis could shed light on these disturbingly high figures.

Several studies of dementing illness assume that costs can be calculated by taking the proportion of nursing home residents with dementia and multiplying by the overall costs of long-term care. That assumes that all long-term care for individuals with dementia is *caused by* their dementia, an assumption that creates many potential inconsistencies. One problem is best explained by analyzing an even larger disabled population—those with arthritis. Symptomatic arthritis is roughly three times more prevalent than severe dementia in the population over 64. Its prevalence in nursing homes approximates that of dementia. Cost estimates that assumed arthritis caused nursing home placement would thus yield figures as high as those for dementia. Yet each disorder cannot account for half of all costs. Similar analyses could be done for residents with partial deafness, visual impairment, or incontinence, each highly prevalent in nursing home populations. The difficulty in determining *why* an individual needs personal or nursing services limits the interpretation of simple cost projections.

Although it is more plausible that dementia directly causes institutional placement than that arthritis does, no study has confirmed this. The rigorous costs studies that can be performed (as in the case of incontinence, for example) presume carefully constructed models of care that do not exist for individuals with dementia. As a result, the fraction of nursing home costs due to dementia have not been estimated reliably. Yet cost projections for such care are important in considering policy changes that would promote delivery of services to persons with dementia. Information about costs and use rates for services would thus be quite useful for determining long-term care policy.

One study attempted to estimate the costs of nursing home care due directly to dementia, and estimated that 3 percent of all elderly people in nursing homes were admitted because of such conditions, with subsequent costs of $1 billion (in 1983 dollars). That figure is almost certainly a significant underestimate because of the strong incentives for underdiagnosis of

Informal care falls disproportionately on women. The very late onset of most dementing illnesses often means that a woman in her fifties or even late sixties may be the primary caregiver.

dementia in nursing homes. That study also reported 36 percent higher labor costs for residents with dementia, in contrast to a 6 percent figure found in New York State. Which is the correct figure for the costs of caring for those with dementia is purely speculative; each may be accurate for its own sample. The New York figure, for example, included a large number of nursing home residents who did not have significant functional impairments, and who may have required less care. Given uncertainties in the accuracy of diagnosis, type of service provided, and sensitivity to uncontrolled economic factors, using current estimates to predict costs of public policies should be done only with great caution.

Costs of Informal Long-Term Care

Most studies report that the majority of long-term care is delivered outside nursing homes—in board and care homes, adult day care centers, and patients' homes. Costs are extremely difficult to estimate, and most overall projections necessarily underestimate this component. One recent study based on a national sample of long-term care recipients estimated that 1.2 million Americans were receiving informal care. That figure compares to the estimated 1.4 million people in nursing homes. Some authors have estimated that 70 to 90 percent of long-term care is informal care, but it is unclear whether these estimates refer to numbers of persons, proportion of services, or some other measurable factor. If it is true that only 1.2 million Americans now receive informal care, then the magnitude of the problem may be less than previously stated—and the cost implications proportionately less worrisome to Federal, State, and local governments.

Costs of informal care include the wages and salaries forgone by family members caring for patients, the lost productivity that results when experienced workers leave the work force to care for relatives, and the stresses borne by patients and their families. The stress induced by loss of mental functions and personality change is enormous for individuals with dementia and for their families, and can lead to illness among caregivers. Such stress can be exacerbated by difficulties in finding and coordinating services to relieve the caregiving burden.

The bulk of informal care is delivered first by spouses, then by children (especially daughters). The burden falls disproportionately on women. The very late onset of most dementing illnesses often means that a woman in her fifties or even late sixties may be the primary caregiver. The efforts of spouses and children are not generally captured by economic surveys—the costs of caring are hidden because no one pays for them directly.

A few indirect indicators of cost have been identified. Of those responding to the national survey conducted for OTA—which, because the sample was drawn from the national mailing list of ADRDA, likely represents more well-to-do families than average—30 percent reported they had "cut back sharply" in spending in order to care for their affected relative, 10 percent reported some impact, 22 percent noted little or no impact, and 48 percent had not used their own funds at all. (These figures add up to over 100 percent because of multiple answers from some respondents.)

A survey of women in Philadelphia found that 28 percent of those taking care of dependent mothers had quit their jobs to give care at home, and a similar proportion were considering it or had reduced their hours of work. A study of a national sample of long-term care recipients found 9 percent of caregivers had quit their jobs. Researchers studying the social breakdown syndrome (a combined index of functional limitations and difficult behavior) concluded that "most of the functional limitation and troublesome behavior occurring in the community is unrelated to the presence of a mental disorder in the elderly person. Nonetheless, persons with dementing disorders contribute to the community burden of disability disproportionately". These studies are further indications of the cost of informal long-term care for patients with dementia.

Finally, two recent studies have been combined to estimate the community costs of caring for those with dementia. A small pilot study of 19 community-dwelling older Americans estimated average costs at $11,700 (in 1983 dollars) to take care of someone with dementia at home, based on what the care would have cost if families hired outside caregivers at prevailing wage rates. This study yielded national estimates of $26.7 billion for such care.

Costs to Government

Costs borne by government are of special interest to policymakers. The amount is not known and has not been specifically analyzed in any major national survey. Several factors suggest the services needed by individuals with dementia may be more costly than for other long-term care populations. The duration of nursing home stay for those with chronic brain syndrome and senility in the 1977 National Nursing Home Survey was 5 percent longer than average. That figure significantly understates the likely length of nursing home stay for residents who enter *because* of dementia, for it is averaged over a diverse group of residents who stay for shorter periods. Those with chronic brain syndrome who are still in a nursing home at 90 days are expected to remain approximately 3 years (1,104 days), much longer than for any other diagnostic group. The average expected stay at time of admission is 97 percent greater. (These data are not specific to dementia patients, however, because while those in the category of "chronic brain syndrome" are largely residents with dementia, other groups—including a fraction of adults with mental retardation—are also included.)

Residents staying longer in a nursing home are more likely to spend down to Medicaid eligibility as they run out of financial resources by paying for care, although that has not been confirmed specifically for those with de-

Individuals with dementia are more likely to be publicly subsidized by the Medicaid program and their care is more expensive than average nursing home residents.

mentia. The RUG-II long-term care demonstration project in New York State found that patients with diagnoses indicating dementia had levels of disability 6 percent higher than average. That higher level of disability would lead to a higher level of care—and thus cost—in turn causing increased State and Federal payments to nursing homes for such residents under the RUG-II payment system. Indirect analysis thus suggests that length of stay and level of disability are both higher for residents with diagnoses indicating dementia, and that **individuals with dementia are more likely to be publicly subsidized by the Medicaid program and their care is more expensive than average nursing home residents.**

A range of long-term care costs can be estimated. The maximum possible cost would assume nursing home care for all with severe dementia, with estimates in the range of $33 billion (1.5 million residents times $22,000 per year average cost of nursing homes). The $22,000 is calculated by dividing total estimated costs for nursing homes in 1986 ($32.8 billion) by the estimated number of nursing home residents (1.493 million). That calculation accords well with one estimate based on a direct survey of 25 nursing home residents with dementia, which found costs of $22,500 per resident per year (in 1983 dollars). If the Federal Government paid 30 percent of this, then its costs would be roughly $10 billion.

The $10 billion figure has a misleading ceiling, however. A more realistic figure for government costs is based on the assumption that half of current nursing home residents have dementia and that Medicare nursing home payments are not for dementia. That hypothesis yields an estimate of $4.4 billion for the Federal Government and $4.1 billion for the States in 1986. That estimate implies that **the Federal and State Governments are each bearing roughly 10 to 15 percent of the overall costs of long-term care for those with dementia**, with the remainder coming from individuals. (Some individual payments, however, also come indirectly from government through social security, VA pensions, and Supplemental Security Income, which provide over 45 percent of income for those over 65.) These estimates are necessarily quite imprecise, and more refined service planning will require much better information and analysis.

The amount of long-term care covered by government programs depends on several factors: degree of subsidy of services, access to services, eligibility criteria for programs, range of services provided, and method of payment. Expanding eligibility, access, range of services, or degree of subsidy would increase government costs, while narrower eligibility or restricted

access to facilities would either reduce overall costs or shift expenses to individuals and families.

COORDINATING SERVICES FOR THOSE WITH DEMENTIA

Although several chronic disorders of old age increasingly confront the American health care system and cause people to need long-term care, several features of dementia make it especially difficult to coordinate services for anyone with this condition. Medical, mental health, and social services are frequently adapted only poorly to the needs and abilities of those with dementia. Services are typically intended for targeted populations, and those with dementia can "fall through the cracks." Families are often referred from agency to agency, each of which may exclude individuals with dementia from their services for different—and legitimate—reasons.

That need not be the case. In some regions, referral networks and family support groups have been established to deal with this problem. Services adapted to patients with dementia are increasingly common, but still serve only a small fraction of the total population. For now, many individuals are left in an administrative limbo between services intended for aged, mentally ill, and acutely ill Americans.

Some States, local governments, or organizations have developed innovative and effective methods for delivering and coordinating care. The ADRDA chapters in Portland, OR and Atlanta, GA, for example, have developed in-home respite programs. The Family Survival Project and On-Lok have both coordinated and managed financing of a wide range of services in the San Francisco Bay area. These programs demonstrate that services for patients with dementia can be provided and financed successfully.

Several States have commissioned studies, developed plans, or established special programs that cover individuals with dementia. Georgia, Illinois, Kansas, Maryland, Massachusetts, Rhode Island, and Texas have issued major reports. Minnesota has produced a comprehensive plan to serve those with brain impairments. California has passed several bills to fund pilot projects and is preparing a Task Force report. These States have taken the lead in studying the needs and planning services for those with dementia.

The Care System

The system for taking care of individuals with dementia includes a wide range of services provided in many settings. The informal care system consists of family, friends, and communities. The formal system consists of government agencies and nongovernmental organizations whose primary purpose is to provide services. Most of the needs of those with dementia are met by the informal care network. Formal service providers are usually used when the informal care system breaks down (e.g., a caregiver moves, gets sick, or dies) or when informal supports are not available (e.g., those without families and living alone). Surveying the history of formal services, two researchers observed that:

Families are often referred from agency to agency, each of which may exclude individuals with dementia from their services for different—and legitimate—reasons.

> . . . public policy, in the last 50 years, has responded to the demographic imperatives of an aging society unevenly. In the two areas of income maintenance and medical services there has been substantial, and for the most part effective, response. But public policy has faltered in the area of health/social services.

People 65 or older have become much more economically independent, largely as a result of greater general affluence and Federal income support programs—primarily Social Security, government pension plans, and Supplemental Security Income. Medicare, the main Federal health program for those over 64 or with a disability, has broadened access to acute medical and short-term transitional care. Medicaid, the health program jointly funded by States and the Federal Government, has increased access to acute medical care for the indigent and become a major funding source for long-term care of the elderly. Long-term care for those who are not indigent, and social services in general have not been as heavily subsidized by the Federal Government.

The protracted course of most dementing illnesses often leads to years during which an affected individual needs constant supervision. Most of the caregiver's activity is directed not at relieving medical problems, but rather at preventing the patient from inflicting harm and at enhancing the quality of the individual's life by taking advantage of preserved mental and physical functions. Those with dementia, for example, often can sing after they lose the ability to speak in long sentences, and they typically retain emotional responsiveness long after their intellectual functions are severely impaired.

Long-term supervisory care of the sort needed for someone with dementia is a service not generally covered by government-supported programs (except for the indigent). In addition, government programs usually focus on the person needing care; yet the person and caregiver function as a unit in most cases of dementia. Hiring a trained supervisor occasionally to watch and take care of someone with dementia gives caregivers respite—time needed to perform routine errands, socialize, or reinstate a sense of their own lives. Such services are not widely available, and formal programs generally do not cover them.

The system of care for those with dementia has several components. Patients must be medically evaluated, their medical illnesses treated, the severity of their illness assessed, their care needs identified, various services coordinated, and use of services financed. Each of these functions must

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be performed for each person. The ideal situation is a "continuum of care" in which the individual's informal supports and formal resources are assessed, and services identified and provided according to varying needs at different times. The system rarely functions smoothly, however, and the long-term care part of the system is particularly noted for its gaps in services and the paucity of financing alternatives.

Inventory of Services

In the survey undertaken for OTA, those caring for individuals with dementia were asked about their assessment of the importance of various services (regardless of current cost and availability constraints). The following 10 services were listed as most important, starting with those most often rated "essential or most important":

1. a *paid companion* who can come *to the home* a few hours each week to give caregivers a rest;
2. assistance in *locating people or organizations* that provide patient care;
3. assistance in *applying for government programs*, such as Medicaid, disability insurance, and income support programs;
4. a *paid companion* who can come to the home for *overnight care* so caregivers can go away for one or more days;
5. *home care* to provide personal care for the individual with dementia, such as bathing, dressing, or feeding in the home;
6. *support groups* composed of others who are caring for individuals with dementia;
7. *special nursing home care* programs only for individuals with dementia;
8. short-term *respite care* in nursing homes or hospitals to take care of individuals with dementia while the caregiver is away;
9. *adult day care* providing supervision and activities away from the home; and
10. *visiting nurse* services for care at home.

In-home care, information about availability of services and government programs, and various forms of respite care were all highly ranked in the survey. These services do not exactly match those now available. Many of the services could be provided in a variety of settings, or by more than one type of professional.

Services are generally provided by agencies that focus on particular target groups in the population. The Federal Government funds services through several programs, including:

- *Medicare*, providing acute medical services for those at least 65, disabled, or suffering from end-stage renal disease;
- *Medicaid*, a joint State and Federal program to provide acute and long-term care for those with low income;
- *Social Services Block Grants*, under title XX of the Social Security Act—the services are not specified by the Federal Government, and States may provide foster care, adult day care, home care, homemaker services, meal preparation and delivery, transportation, or other services;
- *Supplemental Security Income*, a Federal program that makes monthly payments to the aged, disabled, and blind with incomes and assets be-

The protracted course of most dementing illnesses often leads to years during which an affected individual needs constant supervision.

low a Federal standard—individual States may supplement the Federal benefit to cover specific groups, such as those in board and care facilities, and can also cover services such as home care and homemaker services;

- *Services for the Aged*, under title III of the Older Americans Act—the range of services and eligibility are determined by States and Area Agencies on Aging (which are affiliated with the Administration on Aging); services may include adult day care, home care, homemaker services, transportation, telephone reassurance, senior center activities, and others;
- *Mental Health Services*, under Mental Health Block Grants to the States—the services include family counseling, drug use counseling, and support groups, and may include diagnosis and treatment in some areas; and
- *Income Programs*, under Social Security and government pensions programs—Social Security accounts for 37.6 percent and government pensions for 8.5 percent of the income to couples over 64; for individuals, the figures are 44.5 percent from Social Security and 7.8 percent from government pensions.

Government programs thus can overlap extensively in providing services for persons with dementia, can leave gaps in available services, and can vary in coverage from region to region and from one person to another. In addition to variable coverage, there is also variability of how services are organized. Services are usually organized according to the agency providing them. One study observed:

> Health services for the aged are multiple, parallel, overlapping, and noncontinuous and at the very least confusing to the elderly consumer. Rarely do they meet the collective criteria of availability, accessibility, affordability, or offer continuity of care in a holistically organized system. Planning for health services for the aged is similarly confused. Parallel systems of service have their own planning mechanisms. As a result, the various planning efforts overlap, contradict, and are unrelated one to the other. Virtually all the services are funded by differing public money streams and have varied administrative arrangements, widely ranging eligibility requirements, and different benefits for the same or similar services.

Government and nongovernment programs are similar in grouping services into acute medical services, long-term care services, mental health services, senior services, and social services. The specific services included under these groupings often cover similar services and leave gaps among others. Personal care service may be included as a social benefit, a long-term care benefit, or in some cases a medical benefit. In most areas, how-

ever, it would not be available under any agency programs. Some of the services are noted in table 5. The settings in which the services are provided can be either residential (where the client lives) or nonresidential (a place the client goes to obtain services). The settings most often used are listed and briefly defined in table 6.

Senior Services

Although dementing conditions are increasingly prevalent with age, only a minority of those in any age group ever develops dementia. Services for older Americans are usually targeted at the needs of the greatest number, and include senior centers, transportation, counseling, and homemaker chores. These are important services, but many programs exclude mentally impaired individuals, and many services useful to most older Americans are not helpful to those with dementia. Departments of aging and Federal agencies have increasingly focused on "frail" elderly individuals in recent years, but this grouping includes a heterogeneous population with a large variety of medical conditions.

Dementing conditions are among the most prevalent and severe age-associated diseases. But recognition of this fact is relatively recent, and services have not fully adapted to the needs of those with dementia. Under the Administration on Aging, several Area Agencies on Aging and Long-Term Care Gerontology Centers have established programs on Alzheimer's disease, but these serve only a small fraction of those with dementia. In most areas, services for the elderly population do not include those specifically intended for individuals with dementia, and are poorly adapted to their needs. Although many commentators question whether services should be made available to those with dementia that are not available to similarly disabled groups, the degree of mismatch between services and the needs of persons with dementia could clearly be reduced without creating special eligibility groups.

Table 5.—Care Services for Individuals With Dementia

Adult day care	Patient assessment
Case management	Personal care
Chore services	Personal emergency response systems
Congregate meals	Physical therapy
Dental services	Physician services
Home delivered meals	Protective services
Home health aide services	Recreational services
Homemaker services	Respite care
Hospice services	Skilled nursing
Information and referral to services	Speech therapy
Legal servcies	Supervision
Mental health services	Telephone reassurance
Occupational therapy	Transportation
Paid companion/sitter	

SOURCE: Office of Technology Assessment, 1986.

Most of the caregiver's activity is directed not at relieving medical problems, but rather at preventing the patient from inflicting harm and enhancing the quality of their life.

Table 6.—Care Settings for Individuals With Dementia

Residential settings:

In-home services may include home health care, personal care, chore services, and homemaker services to the client's house, apartment, or other residence. Some in-home health services are provided by home health care agencies, most of which are certified by Medicare and must meet Federal standards for staffing and range of services. Other services are provided by community agencies funded by Federal, State, and local governments or nongovernmental organizations. Such agencies are generally not licensed or regulated.

Nursing homes are health care facilities that provide 24-hour care, nursing, and personal services in an institutional setting. Most are certified to provide care under Medicare and Medicaid to eligible residents, and are regulated by States, subject to Federal and State standards.

Board and care facilities are nonmedical residential care facilities that provide room and board and variable degrees of protective supervision and personal care. These range in size from foster care units with a few residents to large domiciliary facilities that house several hundred people. Many board and care facilities are licensed by State governments, but regulations are generally limited to physical structure and fire safety rather than patient care.

State mental hospitals are generally large State-funded institutions that provide acute and long-term psychiatric care primarily for mentally ill people, but also for some patients with dementia—especially those with behavioral symptoms that are difficult to manage.

Hospitals are facilities for medical care of those temporarily residing in them. The primary services available are diagnosis and treatment, but hospitals also often serve as foci for rehabilitation, case management, counseling, family support. They may also be affiliated with nursing homes, day care centers, home health agencies, or other settings and services.

Hospices are facilities for the care of terminally ill people. The emphasis in hospices is on alleviating symptoms and providing personal support, rather than cure and rehabilitation. Hospice services can be delivered in other settings, if the intent is to diminish suffering rather than prolong life.

Nonresidential settings:

Adult day care centers are day treatment facilities, some of which provide intensive medical, physical, or occupational therapy. Others provide primarily social activities and personal services for several hours during the day. Adult day care centers are licensed by some States, and must meet fire and safety codes of local jurisdictions, but are not subject to Federal regulation unless they provide services reimbursed by Medicare or Medicaid.

Community mental health centers are psychiatric and psychological treatment facilities that provide a variety of mental health services for people with acute and chronic mental illnesses. Most services are provided on an outpatient basis. Most centers were originally developed in accordance with Federal regulations tied to Federal funding but are now regulated by States and funded by them, supplemented by Federal funding through Mental Health Block Grants.

Outpatient facilities and clinics are medical settings for diagnosis and treatment of diseases. They may also become involved in delivering other services such as case management and counseling.

Senior centers are facilities intended for use by older Americans. They are often funded by a combination of private charity and local, State, and Federal Government contributions. Day care, recreational activities, family support, case management, and mental health services are available at some but not all senior centers.

SOURCE: Office of Technology Assessment, 1986.

Acute Care Services

Acute medical care for dementia includes identifying symptoms, diagnosing their cause, and treating illnesses discovered in the diagnostic process. Diagnosis and medical treatment for dementia are generally covered by insurance and government programs to the same extent as other medical conditions. Patients are not excluded from eligibility for acute medical care because of the nature of their symptoms. One inequity, a limitation of outpatient psychiatric care, has been addressed in recommendations of the DHHS Task Force on Alzheimer's Disease, but that represents a relatively small component of the acute care needs of those with dementia.

Methods of prevention also need attention in the acute care system. While there is no known way to avoid the most common dementia—Alzheimer's disease—diet, personal habits, and medical care can prevent many of the other disorders (e.g., diet can influence the risk of vascular disease and thus vascular dementia, and cessation of smoking can reduce the likelihood of lung cancer with spread to the brain—one of the most common types of brain tumors in those over 64). Even if the disorders causing dementia cannot be prevented, however, excess disability related to them can be reduced—preventing unnecessary suffering and costs of medical attention—avoiding infections (through vaccination and prompt treatment), careful use of medications (to avoid side effects), and altering personal habits (e.g., stop smoking to enhance lung function and reduce fire hazard, or reduce drinking that intensifies disorientation).

Diagnosis and treatment presuppose trained doctors, nurses, and other health professionals. Alzheimer's disease and dementia were once the province of specialists such as neurologists and psychiatrists, but the aging of the population and increased awareness of dementia are making these conditions also a problem for family practitioners, internists, and other primary care physicians. In addition, there is a movement in medicine to provide specialized training for those dealing with the medical problems of older people. That type of practice, called geriatrics, is not now a medical specialty, but existing medical boards are offering special recognition of geriatric training. Medical aspects of dementia are important in such training because dementia is primarily, although not exclusively, a geriatric problem.

The main issues in acute medical care are: 1) accurate diagnosis; 2) adequate treatment of general medical problems and controllable symptoms; and 3) training physicians, nurses, nurse's aides, and other caregivers. The main mechanisms for improving care are to educate health professionals and to ensure that full diagnostic evaluation and treatments are fairly reimbursed.

Long-Term Care Services

Although no single definition of long-term care has been accepted, it is generally agreed that its goal is to maintain or improve an individual's ability to function as independently as possible, and that services will be needed over a prolonged period, even if only needed intermittently. Medical care

Dementing conditions are among the most prevalent and severe age-associated diseases. But recognition of this is recent, and services have not fully adapted to the needs of those with dementia.

is an essential component, but a variety of other services are also important. "Long-term care" in public policy contexts sometimes means primarily nursing home care, although recent definitions are careful not to so restrict themselves. The White House Conference on Aging, for example, noted:

> Long-term care represents a range of services that address the health, social, and personal care needs of individuals who, for one reason or another, have never developed or have lost the ability for self-care. Services may be continuous or intermittent, but it is generally presumed that they will be delivered in the "long-term," that is, indefinitely, to individuals who have demonstrated need usually measured by some index of functional incapacity.

In terms of spending, however, Federal long-term care policy is mainly concerned with nursing home care. Even within the nursing home population, there is an important division of types and duration of long-term care. Nursing home care covered by Medicare, for example, is intended for those who primarily need medical treatments and intensive nursing care, called "skilled care" (e.g., changing of catheters, postsurgical care, and physical therapy) for short periods (generally less than 2 months). Medicaid coverage includes "skilled" care and also less specifically medical components, called "intermediate" care, but the emphasis remains on medical, as opposed to supervisory, care. Medical care in nursing homes tends to be needed most by those who are there for fewer than 90 days. Those residing in nursing homes for longer periods differ from others in type of disease and in the services needed.

One study found that those with severe dementia admitted to a VA hospital were much more likely than other patients to come from a nursing home and to still reside in a nursing home one year later. Another study found that impairments that include dementia have the longest expected duration of residency in nursing homes among groups studied. Some have called attention to the two different populations in nursing homes, calling them "short-term long-term care" versus "long-term long-term care", or "skilled" versus "chronic" care.

Individuals with dementia are likely to be in the long-stay group, needing supervisory and personal care more than medical attention. One analysis estimates that those with dementia constitute 60 to 70 percent of the long-stay group, making dementia one of the major determinants of those staying longer than 90 days in nursing homes. The distinction between short-

and long-stay patients is particularly relevant in considering the potentially catastrophic costs of nursing home care. Catastrophic costs would accrue primarily to the long-stay residents of nursing homes. Five percent of Americans 65 and over are in nursing homes at any one time, but only 3.5 percent are long-stay patients. That implies the risk of incurring catastrophic long-term care costs is restricted to a smaller fraction of the population than is often cited, and makes risk-sharing through insurance more practical.

Nursing home care is by far the largest cost component of long-term care. Costs vary from region to region, ranging from just over $750 per month to over $3,000.[1] A recent study estimates that out of pocket costs for hospital care will account for $3.3 billion of the $63 billion total (5.2 percent) spent on inpatient services, and $600 million of the $5.8 billion (10.3 percent) on outpatient services in 1986 (see figure 5). That estimate contrasts with $16 billion in out-of-pocket payments of the estimated $32.8 billion (49 percent) spent on nursing home care. (The projection of 1986 costs differs from the $38.9 billion used by the Health Care Financing Administration cited earlier—as it is based on a different economic model.)

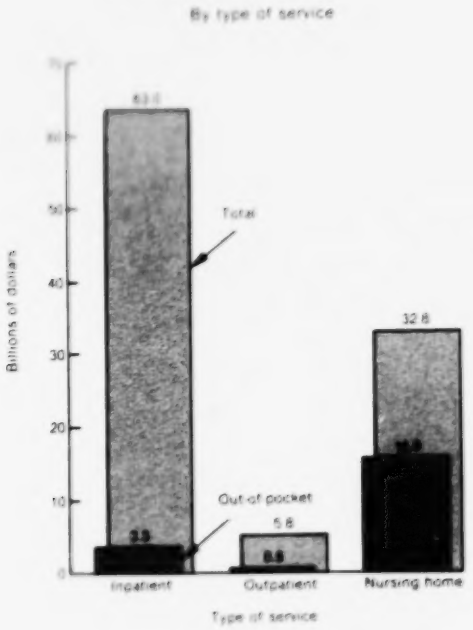
Direct comparisons between hospitals and nursing homes are somewhat misleading, however. Nursing home and hospital costs include several components such as room and board, laundry, meal preparation, and cleaning. Residents of nursing homes and hospitals would pay for such "basic" living costs even if they were healthy and not in either facility. Other services are needed because of disability, such as nursing care and access to diagnostic treatment facilities, and these costs can be attributed to illness. Yet nursing home and hospital charges do not separate basic from medical service components. Comparisons of nursing home and hospital costs should compare the costs due to illness, not overall costs. The proportion of basic living costs is higher for nursing homes than hospitals, accounting for some of the discrepancy in what is covered by insurance and health care programs. It is unlikely, however, that basic living costs account for all or even most of the differential coverage. There is even evidence to suggest that hospitals are more expensive than nursing homes in delivering the same services, and costs in hospitals would more likely be covered by insurance or government health programs.

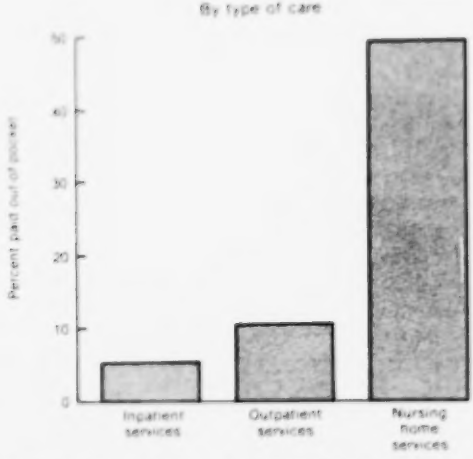
The availability of nursing home beds varies dramatically. In Wisconsin there is a surfeit of beds, particularly in the summer. In other States, health systems agencies or other health planning boards have deliberately restricted the number of nursing home beds available in order to reduce costs under Medicaid. They have done so by using a process called certificate-of-need legislation, requiring a facility to receive State approval before adding beds. The constraint in number of beds has increased pressures for new beds by creating an unmet demand in many States.

The dearth of insurance and Medicare coverage of long-term care (particularly for stays of more than 90 days) is not widely recognized by most

[1]These figures are taken from fiscal year 1982 costs for intermediate care facility reimbursement in Kansas under Medicaid ($25.11 per day) as the minimum, and for a proprietary nonprofit facility in New York (over $100 per day) as the maximum. The Kansas figure is taken from Health Care Financing Administration data organized by the American Health Care Association.

Figure 5.—Out-of-Pocket Expenditures by Type of Service and Care, Estimated for 1986





SOURCE: ICF, Inc., "The Role of Medicare in Financing the Health Care of Older Americans," submitted to American Association of Retired Persons, July 1985, table 21, adapted by the Office of Technology Assessment.

older Americans. A survey of elderly people performed by Gallup for the American Association of Retired Persons showed that 79 percent believed that Medicare would pay for all or part of their nursing home care. Another survey found that only 25 to 47 percent of those asked knew that Medicare does not cover a 6-month nursing home stay. Yet Medicare covers less than 2 percent of expenditures for nursing homes, and private insurance pays for less than 1 percent.

Medicaid is a program intended only for the indigent, and eligibility is contingent on nearly complete depletion of financial resources. Two recent surveys of older people in Massachusetts showed the high risk of families "spending down" to become financially eligible for Medicaid coverage soon after admission to a nursing home. Among those 75 and over, from 57 to 72 percent would become Medicaid-eligible by the end of one year in a nursing home; the figures for those over 65 were 57 to 83 percent (depending on marital status). Figures for other areas will differ significantly because Medicaid varies in coverage and eligibility from State to State.

Social Services

Social services include housekeeping, transportation, and assistance in daily living (e.g., dressing, eating, shopping, meal preparation). Social services emphasize providing clients with what they need but cannot do for themselves, regardless of why they cannot do them. These services can be provided at the client's home or in community facilities, and not only at specialized medical or mental health centers. Many services, such as assistance with dressing or meal preparation, are needed by most individuals with dementia.

The home services needed by individuals with dementia are a particularly troublesome public policy issue. Medicare home health benefits are intended for use by those who would otherwise be accepting medical care in a hospital or nursing home. Although meal preparation, supervision, and personal care are the services most frequently needed by individuals with dementia at home, they are not covered by Medicare (or by Medicaid in most areas). Some social service agencies include those with dementia among their eligible population groups. The need for those delivering services to be trained to deal with the behavioral problems and mental confusion associated with dementia, however, may prevent some agencies from including persons with dementia in their client groups. In some regions, social services are coordinated with long-term care, health care, mental health care, or senior services (e.g., providing transportation to day care centers or delivering "meals on wheels"). In most areas, however, social services are only poorly coordinated with other services. Yet these services are among the ones most desired by caregivers and are significantly less expensive than home *health* care.

Medical and other health and social service administrators are reluctant to increase the range and availability of home services in some areas, however, because of anticipated escalating costs. They fear that such services would be abused by a variety of people who are not ill or needy. The potential for abuse would be reduced if recipients of the service were required

A pattern of care is emerging that emphasizes medical evaluation and drug management, combined with mental health care in nursing homes and day care centers that coordinate their services with social and aging services.

to have an assessment of needs (based on diagnosis, functional disability, or some combination of factors), but it is not clear that there is a practical assessment method available that is cheap, accurate, reliable, and auditable.

Inexpensive home care for persons with dementia has been successful in some areas, often sponsored or coordinated by local ADRDA chapters or Area Agencies on Aging. A pilot project to train volunteer caregivers about dementia so they can provide social services in the home is beginning under the Senior Companion Program of ACTION. Such programs rely on funding through charity, volunteers, and nongovernment organizations, and the client's family is usually the source of payment. That is an economic way to control use. Another method is to set an upper limit on subsidized benefits by limiting the total days or budget, or through a voucher system.

Mental Health Services

Until the 1960s, institutional care for individuals with dementia was largely provided in State mental hospitals. Public policies to reduce the population in such facilities decreased the number of persons with dementia in mental institutions, and the availability of joint Federal and State coverage of nursing home care accelerated this trend. One careful investigation suggests that older persons who once would have been sent to mental hospitals are now referred to nursing homes (47 of 50 residents in one nursing home—94 percent—had a mental disorder). The displacement has not been due to transferring residents directly from mental hospitals to nursing homes, however. (In the study just cited, only 1 resident out of 50 had been so transferred.) The data are most simply explained by older persons with behavioral and cognitive symptoms being preferentially admitted to nursing homes instead of mental institutions in recent years.

The behavioral aspects of dementia are among the most difficult symptoms to manage, and facilities using a mental health model (focusing on adapting to the individual's behavior) rather than a medical one (focusing on correcting a disability) appear in preliminary studies to benefit people more. A pattern of care is emerging that emphasizes careful medical evaluation and drug management, combined with a mental health model of care in nursing homes and day care centers that coordinate their services with available social and aging services.

Persons with dementia become dependent because of their inability to understand the intricacies of daily life. Although symptoms are caused by physical brain damage, dependency is induced by loss of *mental* function, rather than *physical* disability. That contrasts with arthritis or hip fractures, for example, where immobility is directly caused by joint and bone problems, and the disability is easier to observe and measure. There is less opportunity for confusing physical disabilities than mental ones, and concern for overutilization of health care services overall has engendered a conservative approach that puts the burden of proof on individuals with mental symptoms to show the legitimacy of their needs.

The behavioral symptoms of dementia often relegate individuals to categories for which coverage by health programs is ambiguous. They may be eligible for medical care, mental health services, both, or neither. In times of budget restraint, programs typically cut back on services not central to their mandate. Dementia is at the margin of both medical care and mental health services. Patients may be seen by a family physician, an internist, a neurologist, or a psychiatrist, and each specialty has its own orientation for diagnosis and treatment. Agencies delivering mental health services may exclude someone with dementia because their resources only cover drug rehabilitation, for example, or rape counseling, and yet health care programs typically focus on acute rather than long-term care. Those with dementia may thus be left with access to no services except family care at home or nursing home placement.

The Federal Government supports mental health research at the National Institute of Mental Health (NIMH) and pays for some mental health services through payments to States. Federal and State Governments jointly fund Community Mental Health Centers (CMHCs) throughout the Nation, but these must deliver a full range of services to all population groups. A recent survey found that at most 20 percent of CMHCs had programs for persons with dementia and their families; these programs were five times as common in CMHCs specialized in mental health for older individuals, and they were heavily used where available. NIMH has established three Clinical Research Centers on Psychopathology of the Elderly, two of which focus on Alzheimer's disease. These are important centers for investigating individual needs, treatment methods, and family support mechanisms. They also train many clinicians who can then care for patients in their practice. Yet because of the extent of the problem, the NIMH national centers and those CMHCs covering dementia miss large sections of the population. Findings from these centers must be applied nationwide before most Americans can benefit from them.

Mental health services for *caregivers* are also important. That applies to family caregivers as well as professionals and aides working in home care services, day care centers, and nursing homes. Services for caregivers include support groups, counseling, and treatment of stress-induced disorders. Much of the support for families has been provided by volunteer groups such as ADRDA and dozens of smaller local organizations at little cost to taxpayers. Such support cannot cover the full range of needs, however, and large geographic areas are still not served by such groups. Expanding

the range of services and geographic coverage are both high priorities for ADRDA in its current organizational plan. Services for caregivers in long-term care facilities are not as well organized, and that issue deserves increased attention from home care, day care, board and care, and nursing home providers.

GROUPS OF SPECIAL CONCERN

Several groups are of special concern in policy discussions of care and services for persons with dementia:

- those without families,
- minority and ethnic groups,
- individuals experiencing disease onset in middle age,
- individuals residing in rural areas,
- veterans,
- low-income groups, and
- caregivers.

Each group has special needs and problems not shared by everyone with dementia that influence how providers must adapt services. The first four groups are at special risk of reduced access to services. They represent especially vulnerable populations, and those most likely to benefit from public services. The different risk factors can reinforce one another to identify those in particular jeopardy. A black woman with dementia living in a rural area on low income without a family, for example, would be unlikely to be receiving services but might especially need them.

Those Without Families

Much public interest has centered on problems faced by the families of those with dementia. Yet while many policies designed to improve the situation of someone with dementia rely on relatives or friends who can make decisions about care, finances, or the person's rights, many individuals with dementia do not have families or friends available. A 1975 General Accounting Office study of those age 65 or older in Cleveland, found 13 percent did not have a primary source of help in the event of disability. A recent national sample of long-term care recipients found that 10.7 percent lived alone.

The number without family may be higher for those with dementia because so many are quite old, and likely to be widowed. Extreme old age also increases the chance that someone's children are disabled or deceased. People who are not married are more likely than married individuals to reside for long periods in nursing homes. They are less likely to have access to alternative services such as day care because of difficulty finding the service and arranging for transportation. Informal care directly provided by families and coordination of care often managed by family members are likewise unavailable. Patients without families are thus disproportionately dependent on formal long-term care services such as nursing home care and case management by public agencies. Special methods of identify-

ing and assisting patients without families are available only in a few areas, however, and there is little information about them.

Identifying those without families who may need services is especially difficult, but can be done by alerting police, ministers, grocers, and others in the community to look for older people who may be ill and to refer them to a lead agency. One program that does this is the "gatekeeper" program in Spokane, WA, which links a Community Mental Health Center, an Area Agency on Aging, and 13 other agencies together in a disseminated referral network with a single central process for screening candidates and determining eligibility for services.

Minority Groups

Minority groups have lower average incomes and use fewer public services than comparable groups in the general population. They frequently have different social support systems, religious affiliations, and cultural norms. Disparate minority groups cannot be analyzed as a homogeneous whole. Few studies have been done of older Americans in minority groups in general, and almost no information exists on dementia in particular. Although the prevalence of dementia appears similar across national boundaries and races, a few variations have been reported. The high rate of hypertension among blacks and Native Americans may make them more likely to develop vascular dementia. The ratio of vascular dementia to Alzheimer's disease also appears higher in Japan, and surveys of Chinese and Taiwanese populations report dramatically reduced prevalence of dementia (although such differences may be due to reporting rather than true prevalence).

International studies of prevalence rates in different races can give clues about the expected prevalence among those minority groups in the United States, but rates in native countries can be affected by economic and cultural factors. Life expectancy among most minority groups is rising with more older individuals at risk of developing dementia. Minority groups also tend to be undercounted in the census, so projections of dementia among them would understate the true prevalence in the population. Each of these factors suggests that more minority elderly Americans will develop dementia, and that a higher proportion of persons with dementia will come from minority groups. Direct assessment of the prevalence and cause of dementia among minority groups in the United States is therefore important.

Disability among members of minority groups is higher, but statistics show lower use of many public services. That pattern might be altered, however, by programs designed for specific minority populations. The Keiko nursing homes in Los Angeles focus on the needs of Americans of Japanese descent, while the successful On-Lok program in San Francisco serves a population that is 70 percent of Chinese descent.

Social, medical, and long-term care services are usually structured for the majority population and frequently are only poorly adapted to the cultural norms of minority groups. Most minority groups, particularly those with sufficient concentrations of people in an area, have informal networks

The finances of a person with dementia and the caregiver are closely commingled, so the costs of care can have a catastrophic impact on two or more people, not just the ill person.

of family, religious, community, and service supports. These supports generally are also linked at the local level with service providers, but Federal and State Government policies frequently fail to permit local agencies sufficient latitude to take advantage of minority group social supports.

Service systems for minority groups work best when they take advantage of existing supports within the community. Black Americans tend to rely on churches for social and emotional support; Hispanics often have a network of *consejeras* (informal counselors) or *servidores* (people who informally take on the role of providing information and support); the Chinese have *Yau Sum* ("person of good heart"); American Japanese may have *Shinsetsu sua hito* ("kind person") networks; and Native Americans have tribal councils and designated spiritual leaders. The capacity of such informal supports, as in the majority culture, can be exceeded. Individuals with dementia typically go beyond the ability of the informal system to adapt at some point in the illness, but that point can be delayed by programs that foster informal networks, or that at least do not interfere with them.

Although family support groups have grown rapidly throughout the United States, the early growth has been concentrated in the majority Caucasian population. In the survey conducted for OTA, drawn from the ADRDA national mailing list, 94.8 percent of respondents were white, 1.6 percent black, and 0.7 percent other (2.9 percent did not respond to this question). That compares with 88.5 percent white, 8.8 percent black, and 2.7 percent other minority in the U.S. census of those aged 55 to 64. Family support groups can, however, be successful among minority groups, as demonstrated by an Hispanic support group started in the Tampa area. Outreach to minority groups is high on the agenda of many of the support group organizations, including ADRDA.

Individuals Experiencing Onset of Dementia in Middle Age

The majority of dementing illnesses do not begin until after age 65. An estimated 5 to 10 percent of persons with dementia, however, develop the disease in middle age. The exact proportion of cases that begin before age 65 is uncertain, but an estimated 75,000 Americans under 65 have severe dementia.

The problems caused by onset in middle age add to those associated with later onset. Individuals who are working almost invariably lose their jobs and are usually unable to find other employment. They and their families

not only suffer loss of income, but also incur substantial medical expenses for diagnosis and treatment, often complicated by loss of health insurance caused by unemployment (although this effect should be mitigated by recent changes in Federal law that require extension of health insurance for most categories of employees).

In addition, those in middle age are more likely to have young children with financial and emotional needs, who are less likely to understand declining mental function and personality change. Finally, many families discover that finances have been mismanaged for months or years before diagnosis. In many cases, the persons failed to maintain health, automobile, and life insurance payments, left important bills unpaid, or spent family funds frivolously.

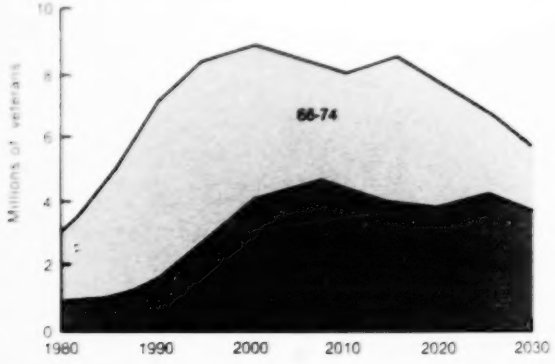
These problems can be compounded by the difficulty in dealing with public programs. A person under 65 may encounter difficulty establishing eligibility for Social Security Disability Insurance (SSDI). The survey done for OTA of those caring for someone with dementia found that 11 percent had applied for SSDI and 35 percent had been denied benefits. That finding is particularly important for those under age 65 because denial of disability benefits also generally precludes Medicare eligibility. Those declared ineligible for SSDI are also barred from Medicare coverage; those found eligible for SSDI must wait a minimum of 29 months until they are covered by Medicare. The House and Senate Appropriations Committees requested that the Social Security Administration address disability policies regarding dementia, in consultation with the National Institutes of Health (conference report on Public Law 99-500).

The number of those developing dementia before age 65 could dramatically increase as a consequence of acquired immune deficiency syndrome (AIDS). The majority of those who develop AIDS also develop dementia due to brain infection by the virus that causes the disease. They thus become dependent on others for medical and daily care. Nine thousand cases of AIDS were reported in the United States in 1985, and 46,000 to 90,000 are expected in 1991; 20 to 30 percent of the estimated 1 to 1.5 million Americans infected by the AIDS virus as of June 1986 are projected to develop AIDS by 1991. If 70 percent of those with AIDS develop dementia, then the proportion of those with dementia under 65 would almost double. There are several uncertainties in that estimate. The mortality of AIDS is quite high and so the duration of illness would be short. The proportion of those with virus infection who develop dementia but not AIDS is unknown, and the duration might be longer for such individuals. The AIDS pandemic is thus likely to dramatically increase care needs for those under age 65 with dementia, but the amount and duration of needed care are highly uncertain—both overall and for each patient.

Rural Residents

Rural residents have access to fewer specialized services, and hence a restricted range of long-term care options. Rural areas may be served by a single general physician unfamiliar with dementia, have only one local hospital, and only one nursing home. Few have adult day care or in-home

Figure 6.—Number of Veterans Age 65 and Over



SOURCE: Veterans Administration, International Working Group, *The Veterans Administration and Dementia: Recommendations for Patient Care, Research, and Training*, October 1985.

services, and participation in family support groups, the few places they exist, may require substantial travel time. Reduced access to services may be exacerbated if there are no family members in the area to help care for the individual with dementia, or if there are no neighbors nearby to provide intermittent help.

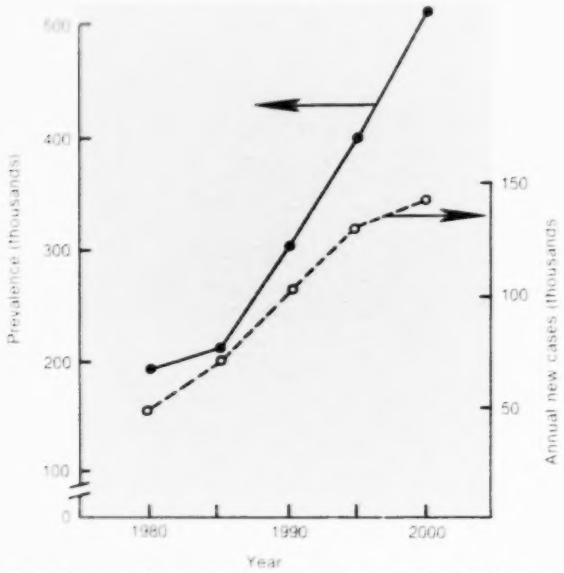
Veterans

The Veterans Administration is concerned about the rising prevalence of dementia among those eligible for its services. The rise in prevalence among veterans will peak 10 to 20 years before it does in the general population because of the special demographics of those who served during World War II, the Korean war, and in Vietnam (see figure 6).

The care received by veterans depends on why and when their illnesses began. The first priority for VA services goes to those whose disability or illness is service-connected. Dementia is only rarely service-connected (e.g., because of severe head trauma). Other services are provided on a space-available basis. Some VA facilities have developed special programs for those with dementia, but VA hospitals do not guarantee access to long-term care or to specialized services for those with dementia (see figure 7). Most VA facilities cover care for diagnosis and treatment of intercurrent illnesses. Veterans Administration hospitals and nursing homes treated over 20,000 veterans with a diagnosis of dementia in fiscal year 1983. Special care units for individuals with dementia have been developed at 12 VA medical centers. Yet the survey of caregivers done for OTA found that 45 percent of those who had applied for extended care were refused VA services, most often because the disability was not service-connected.

For several reasons, the VA system is under increasing political pressure to provide care to those with dementia and other chronic illnesses. First,

Figure 7.—Prevalence and Annual New Cases of Dementia, U.S. Veterans, 1980-2000



SOURCE: Veterans Administration, International Working Group, *The Veterans Administration and Dementia: Recommendations for Patient Care, Research, and Training*, October 1985.

the number of veterans reaching advanced age is expanding rapidly (see figure 6). In 1980, only 3 million veterans were 65 and older, but this will increase to 9 million by the year 2000 (representing 63 percent of all men 65 and older). Second, veterans and their families often expect the VA to cover all care. Explanations that particular illnesses or disabilities will not be covered often are not understood or are rejected, particularly if families know that the type of care they seek is available at VA facilities in other geographical areas.

Those With Low Incomes

Americans with low incomes are particularly dependent on government programs. Lack of income restricts them to those services that are free through charity, subsidized, or inherently inexpensive. A substantial proportion of their low income is directly provided by the Federal Government. Among those 65 and over with less than $10,000 income, for example, social security provides on average 82.2 percent of income, compared with 17.8 percent for those with incomes over $30,100. In addition, the Medicaid program to cover medical services is intended primarily for this group, yet both the lack of awareness and the complexity of the program hinder full use of the benefits. Ironically, those with higher incomes may benefit more from Medicaid, particularly the long-term care component, because

they have easier access to the information needed to obtain eligibility and can afford to enter a nursing home as private pay clients, who later find they have "spent down" to Medicaid eligibility. People with lower incomes cannot pay initially, and nursing homes that have a choice prefer to admit private pay residents because Medicaid reimbursement rates are low.

Caregivers

Middle-aged caregivers are at high risk of becoming secondary victims of dementia. Volunteer groups and government services could productively target this group. The majority of those caring for dependent parents are middle-aged women, a fact that appears to be true not only for dependent older people in general, but also for those with dementia. These women may also be responsible for the care of children or adolescents, or may just be starting careers after their children have left home. Yet family support groups are the only services available to them in many areas.

A recent study of a national sample of long-term care recipients found that roughly three-fourths of caregivers lived with the dependent older person 7 days a week, and only 9.7 percent purchased formal services. Of those caring for dependent older people, 44 percent had done so for more than 1 year but less than 4 years, and over 20 percent had been caregivers for 5 years or more.

Caregivers who are themselves old face different stresses from those in middle age. Older caregivers are more likely to have an illness that increases the stress and health risk of caregiving. The finances of a person with dementia and the caregiver are closely commingled when the caregiver is a spouse, so the costs of care can have a catastrophic impact on two or more people, not just the ill person. Decisions about an individual's legal status (and control of family finances) likewise affect the person with dementia and the spouse alike.

Box A.—A Case History

P was a bookish man with a robust sense of humor. He was an excellent student, had an easy time in college, and received his medical degree in 1947 from Louisiana State University. He did an internship, and several years of residency in pathology and medicine (doing work on kidney physiology with Homer Smith, an investigator of international reknown), and completed a residency in psychiatry. His interests over the years drifted towards Zoroastrianism, Tibetan Buddhism, psychoanalysis, and other widely divergent topics. He practiced as a psychiatrist and teacher for two decades, earning the intense loyalty of a large circle of patients and students.

In the fall of 1975, at age 50, he startled the guests at a dinner party by picking up the meat from his plate, rather than using his knife and fork. Although P had long been regarded as unusual, that was markedly eccentric, and far outside the range of his usual punctilious behavior. Soon after Christmas, his family found he did not remember that Christmas had passed. His humorous anecdotes became fragmented and impossible to follow. He became paranoid, and got lost returning home from work despite having had

the same clinic and home addresses in New York City for many years. In January 1976, he was evaluated by a neurologist who said he had Alzheimer's disease.

The family adjusted to the simultaneous traumas of losing P's substantial income, dealing with his increasing distressing disabilities, incurring large medical bills, and arranging his care. In March 1976, the informal care arrangement broke down under stress, and P was moved to Baton Rouge, Louisiana, to live at his childhood home with his mother. His wife moved to Canada, the country of her citizenship; his daughter found alternative financing for college; and his son left home for college. P's mental symptoms worsened. He could not remember where he was, what had happened to his patients, or why he could not return to New York. He had his first seizure in 1977, and his behavior became too difficult to manage so he was no longer taken to church. Where once he had never been found without a book in hand (he was the sort who would take a book to a picnic), he found it impossible to read. In 1978, he began to wander and get lost (to be picked up by the police), so the outside doors were locked. He began to hallucinate and talk to himself and show increasingly unstable emotional reactions.

In 1980, a day worker was hired to help at home because P could no longer get into and out of bed, and needed assistance eating and dressing. In 1981, his mother developed heart failure and had to be rushed to the hospital. That precipitated a crisis for the family. Nursing homes were regarded as either too expensive or unsafe, so home care was elected. Financial assistance was not available under disability or government programs because P did not require "skilled" care, but rather needed personal care and supervision. Home care services were not available in Baton Rouge in any event. The family, after several days on the phone, hired three "sitters" to cover 24 hours a day (one attendant during the day and two for evening and night). P's condition worsened over the next several years, with uncontrolled movements, inability to talk, and failure to recognize others.

In January 1985, P lapsed into a stuporous state of unknown cause. In early February, he was rushed to the hospital, where aggressive medical treatment was not pursued. Six days after admission, he died quietly at age 60, almost a decade after diagnosis.

POLICY ISSUES

The problems faced by persons with dementia and their families impinge on public policy in many ways. There is no cure, no means of prevention, and no fully effective treatment for most dementias. The government strategies for addressing this public health problem are: 1) to support research in hopes of discovering a cure or means of prevention, and 2) to deliver or facilitate delivery of services for those who develop dementia. The roles played by the Federal Government that are relevant to the problems of dementia include:

- supporting research, including basic science, clinical research, and the study of health care delivery;
- directly providing health care to special populations;
- paying for care through Medicaid, Medicare, Mental Health Block Grants, and VA subsidies.

- training and educating health professionals and caregivers;
- assuring the quality of acute and long-term care;
- planning health and social services; and
- disseminating information on care, research, and services.

Table 7 contains a brief list of some of the most important Federal programs that deliver or fund care for persons with dementia.

Should There Be Special Programs for Dementia?

An discussion of the government's role in this field must consider whether there should be special programs for individuals with dementia. Furthermore, judgments about the fairness and effectiveness of different policies require a clear distinction between special services, entitlements, and research.

Specialized Services

Specialized services for those with dementia include support groups, day care centers, nursing home units, and in-home respite care programs designed specifically to aid those with mental impairment. Such specialized emphasis helps in the training of caregivers and focuses attention on the special problems of delivering services to those with dementia. The existence of specialized services for one group of diseases need not discourage developing specialized services for others. Patients with cancer, for example, do not receive the same treatment as those with heart disease, and yet may be covered under the same medical program (e.g., Medicare).

There is no consensus that persons with dementia should receive specialized services. Yet special care units at nursing homes, special day care centers, special board and care facilities, and even special hospitals for patients with Alzheimer's disease are proliferating. The rationales for such units are the opportunity to improve the care of persons with dementia by having better trained staff and adaptive environments, reduced interference with residents without dementing disorders, and the need for activities that specifically take account of diminished intellectual and communicative skills. Many worry, however, that such facilities will become the repository for neglected individuals. At present, no separate guidelines are available for special care units and programs, and philosophies and methods for administering them differ markedly. The ferment of activity in special care is generally improving care for those with dementia, however, and is generating innovative care techniques.

Special Entitlements

Special entitlements for individuals with dementia would make eligibility for services contingent on a particular diagnosis or type of disability. A special Medicare or Medicaid entitlement for dementia could be created, analogous to the special Medicare eligibility reserved for those with end-stage renal disease (although a special dementia entitlement would be primarily for long-term personal, rather than medical, care). Those favoring special entitlements contend that the problems of patients with dementia are so severe and different from those with other disorders that they deserve spe-

Table 7.—Federal Roles in Dementia Issues

Function	Primary agency or method	Agency delivering service
Research		
Biomedical research	Public Health Service	National Institutes of Health (NIH): National Institute on Aging (NIA) National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) Other NIH institutes National Institute of Mental Health (NIMH) (Alcohol, Drug Abuse, and Mental Health Administration)—the majority of research under the Public Health Service is conducted at universities or medical centers
	Veterans Administration (VA)	VA investigators; geriatric research, education, and clinical care centers
	Department of Education	National Institute on Disability & Rehabilitation Research
Research on health services	National Center for Health Services Research and Health Care Technology Assessment (NCHSR/HCTA)	
	NIMH	
	NIH	
	Health Resources and Services Administration (HRSA)	
	VA	
	Health Care Financing Administration (HCFA)	
	Administration on Aging (AOA)	Long-term care gerontology centers
	National Center for Health Statistics (NCHS)	
	Bureau of the Census	
Direct health care		
	Department of Defense	Military hospitals and clinics
	VA	VA hospitals and facilities; contractors
	Indian Health Service	Indian Health Service facilities
Payment for care		
Medicare (acute care)	HCFA	Hospitals, clinics, institutions, other providers
Medicaid (with States)	HCFA	Providers through State administrative offices
Mental Health Block Grants (with States)		Community Mental Health Centers
Tax policies	Department of Treasury	Internal Revenue Service
Contract care	DHHS	Indian Health Service VA
Training and education		
	AOA	Long-term care gerontology centers
	HRSA	Bureau of Health Professions
	Veterans Administration	Geriatric Research, Education, and Clinical Care Centers; Fellowships; Nurse Training; Interdisciplinary Teams
	Public Health Service	NIH Fellowships and Centers; NIMH Fellowships and Centers
	HCFA (Medicare)	Teaching hospitals
	Student Loan Programs	
Quality assurance		
Acute care	HCFA	Professional review organizations
Nursing home care	HCFA and States (Medicaid)	State certification and inspection offices
Mental health advocacy—block grants to States		
Adult protective services		AOA; others

The sudden increase in awareness about dementia has meant that few centers are expert in care and research on this topic.

Table 7.—Federal Roles in Dementia Issues—Continued

Planning		
	Office of Assistant Secretary for Planning and Evaluation	
	Office of Assistant Secretary for Health (Alzheimer's Disease Task Force)	
	Public Health Service	HRSA NIMH
	HCFA (Medicare and Medicaid services)	
	AOA	Area agencies on aging
	VA (veterans)	
	Department of Defense (military personnel)	
	Indian Health Service (native Americans)	
Information dissemination		
	Public Health Service	NIH NIMH
	Office of Assistant Secretary for Health (Task Force on Alzheimer's Disease)	
	AOA	Area agencies on aging
	HCFA (Medicare and Medicaid eligibility and coverage)	

SOURCE: Office of Technology Assessment, 1986

cial eligibility. Others contend that those with dementia are merely one group among many vying for services in a fragmented health care market. They point to other groups with similar problems in obtaining needed services, particularly long-term care. Other groups also have limited access to long-term care (e.g., adults with mental retardation or adults with spinal injury) and difficulty finding adequate mental health or social services (e.g., schizophrenics or the homeless). Still others may need health services from public programs with limited budgets (e.g., maternal and child health for the indigent under Medicaid).

Some of the consequences of developing special entitlements for dementia can be predicted. A special long-term care program for those with Alzheimer's disease would face several problems. If based on diagnosis, it would be unduly restrictive (eliminating services for those with multi-infarct or other dementias) or it would be vulnerable to inappropriate utilization because of vague definitions of the conditions covered. Making services contingent on diagnosis or a restricted list of conditions would put severe strain on the accuracy of diagnosis. While special diagnostic centers report 90 percent diagnostic accuracy, that proportion would likely drop if there were incentives favoring one diagnosis over another. Physicians wishing to aid

their patients would likely list the diagnosis of Alzheimer's disease in preference to other dementing conditions if there were any room for doubt, thereby increasing the number of persons reported to have Alzheimer's disease even if the true prevalence did not change. If services were triggered by severity of disability, then a method to screen out those with lesser disability would have to be in place. That would likely entail mandatory assessment for eligibility, and would necessitate a measure of mental disability that is quick, accurate, reliable, and auditable.

A special entitlement for dementia, or specifically for Alzheimer's disease, also raises a question of fairness. An adult with spina bifida, Huntington's disease, or multiple sclerosis needs many of the same services as an individual with dementia. A special entitlement restricted to persons with Alzheimer's disease would likely promote conflict among interest groups for different diseases. A broader definition encompassing "related disorders" will be vague and difficult to implement. The prudent course appears to involve providing the services most needed but not restricting their use to *only* those with dementia.

Specialized Research

Although no consensus exists about the risks and benefits of special care or special entitlements, it is generally agreed that specialized *research* on relevant science, clinical care, and service use is essential. Serious study of the large group of people with severe functional disabilities due to dementia has only begun in the past few years, and much more information is necessary before public policies, medical practices, and service use can be rationally assessed. Such information can come only from research that focuses on individuals with dementia. Studies need not deal exclusively with persons with dementia to yield useful information. Those that survey long-term care or mental health in elderly people could shed light on the problems of someone with dementia if they include sufficient information to evaluate cognitive function (measured by a standard scale), service use, diagnosis, assessment of lost functions, efficacy of special care, and costs.

Diagnosis and Treatment

The main policy concern about diagnosis and treatment is rapid dissemination of knowledge to permit accurate diagnosis and appropriate treatment. The primary mechanisms for improving diagnosis and treatment are research and education (discussed in detail later in this section).

Also of concern is how to link medical evaluation to long-term care service planning, patient assessment, and social services. Creating new entitlements restricted to those with dementia would, for example, provide strong incentives to widen diagnostic criteria for those conditions, in order for more patients to qualify for public programs. The fragmented nature, complex organization, limited access, and uncertain eligibility criteria for long-term care services cause problems for individuals with dementia and their families. The physician is commonly responsible for coordinating medical services, but there is no analogous person to coordinate long-term care, mental health, social, and aging services. The concern here is for clients

to have a person to turn to for information, and to begin planning service needs as soon as possible so that long-term care decisions are not made in a crisis atmosphere.

One mechanism to begin service planning would be to refer persons who receive the diagnosis of a disorder causing dementia to another professional or organization that can deal with the family and client in planning and coordinating services. This role is variously referred to by such terms as case management, case coordination, or linkage. Having such a professional available for referral from physicians would greatly improve the rational provision of services, but the costs are uncertain. Results from a national demonstration project to study case management and some alternatives (the Channelling project, supported by the Health Care Financing Administration) will be available soon for analysis, and information from that analysis will bear directly on policy regarding case management.

A third issue related to diagnosis and treatment concerns methods of diagnosis. The National Institute of Neurological and Communicative Disorders and Stroke (NINCDS), NIA, ADRDA, and the American Psychiatric Association each have published general criteria for diagnosis of dementing conditions, but none is specific as to which tests should be ordered and how they should be interpreted. Consensus may not be possible or advisable, but current criteria are not useful for the general practitioner trying to determine the diagnosis of a patient. An NIH consensus conference on diagnosis of dementia will be held in July 1987, and may help address this need.

One recent bill passed by Congress and signed by the President (Public Law 99-509) will establish up to 10 centers for diagnosis and treatment of dementing disorders. These would be distinct in function from the existing biomedical *research* centers, although they might be related geographically and administratively. The State of California has established six such centers, and reports that, even without publicity, the centers cannot meet demand for service. The centers are intended to diagnose and treat local cases of dementia, foster research, provide training for health professionals, aid families, and collect and analyze standardized information of use in planning services.

California reports that budget cutbacks at the State level have seriously impaired delivery of the expected services at the State-supported centers.

Diagnosis and treatment centers could be useful in training, setting standards for care, and focusing clinical research, but they should not be expected to make the diagnosis and treat all cases of dementia in the United States. The cutbacks California has reported could also occur at the national level.

Legal and Ethical Concerns

Decisions about medical care, family finances, and other important topics are often difficult enough even when all parties are mentally competent. They become even more difficult when someone has dementia. Eventually decisions must be made on behalf of the individuals—decisions about driving an automobile, working, controlling financial assets, or participating

in research that may not be of direct benefit. Such decisions are particularly difficult when someone's employment involves professional work that is not closely supervised, such as medicine or law, yet these are jobs in which good judgment is essential.

State and Federal laws include several ways to appoint someone to make decisions for another person. Guardians and conservators can be appointed by a court following a procedure to decide that an individual is indeed incapable of autonomous choice. Durable powers of attorney allow a person to set certain constraints on finances or medical care and to appoint someone to make decisions *before* becoming mentally incompetent. Living wills can indicate what types of medical care an individual would wish to receive or refuse.

Each of these mechanisms for making decisions raises difficult questions. At what point is someone mentally incompetent? That is not a purely medical or purely legal question, and competence (legally defined) depends not only on the individual's mental ability, but also on the type of decision being made. Other questions include who is to oversee the decisions made by an appointed surrogate and how someone can be protected from conflicts of interest. Few of these questions can be directly addressed by Federal legislation. Most are now being decided through the judicial system at both the State and Federal levels. Many States have also passed or considered laws about living wills, powers of attorney, guardianship, and conservatorship.

Legal issues related to Federal programs such as Medicare and Medicaid are also important. A family that receives legal advice soon after a diagnosis of progressive dementia is made may transfer the assets of the person with dementia more quickly, and thus establish patient eligibility for Medicaid sooner. Medicaid law stipulates that patient assets cannot be transferred for *purposes* of establishing Medicaid eligibility, and assets cannot have been transferred more recently than 2 years before becoming eligible. In most cases of dementia, assets would be transferred because of mental incompetence of the patient, but the burden of proof rests with the family. If transfer is completed early in someone's illness, the person is more likely to be eligible for Medicaid by the time nursing home care is needed.

These considerations make asset transfer a particularly difficult issue for families and State Medicaid administrators. Families benefit from early advice to legally transfer someone's assets, but individuals' rights to control their possessions must also be protected. And Medicaid is not intended to pay for the care of those who have impoverished themselves only on paper. Medicaid administrators would prefer to target their resources to those who need medical services and cannot afford them. The degree of responsibility of families in this context is unresolved. Idaho attempted to make children financially responsible for the care of their elderly parents in a 1983 law, but the legislation resulted in few recovered funds, was ruled in violation of Federal statutes, and was politically unpopular.

No clear legal method can resolve the dilemma, and those with different ideological views differ markedly about the form a remedy would take.

The issue might become moot if the incentive to rely exclusively on Medicaid to cover long-term care were reduced significantly. The incentive is strong now because Medicaid is the only public program available, and lower incentives would require a substantially higher rate of private financing (e.g., long-term care insurance, life care communities, or private savings) or availability of alternative publicly financed long-term care services.

Another set of legal problems arises in government income support and health care programs. Those entitled to income and health benefits who are deemed mentally incompetent generally have a "representative payee" designated by the program disbursing funds. The representative payee becomes, in effect, the individual's guardian for social security payments. Yet the legal processes of establishing guardianship are not necessarily recognized by the Social Security Administration, the Veterans Administration, or other government agencies. Legal proceedings may be taken into account, but the agencies' own determinations carry more weight, despite being much less formal and providing less protection for the individual's rights.

Representative payees receive funds for an estimated 4 million to 5 million Americans. The Department of Health and Human Services has been sued on this issue, in *Jordan* v. *Heckler* (U.S. District Court, Western Oklahoma, CIV-79-944-W, Jan. 18, 1985) and the case is pending. Section 16 of the Social Security Disability Benefits Reform Act of 1984 (Public Law 98-460) mandated an annual accounting of representative payees, and sought a report on the proposed accounting system to be prepared for Congress in 1985. A six-page report was submitted in September 1985, but it contained no data on rates of auditing or details about ascertaining mental competence for purposes of assigning representative payees. Nor did it describe procedures for identifying misuse of funds or special safeguards for those judged mentally incompetent who are cared for outside State mental institutions.

Education and Training

Providing high-quality services for those with dementia presumes the availability of trained people to deliver them. The sudden increase in awareness about dementia has meant that few centers are expert in care and research on this topic. Efforts to correct that deficiency have begun in the last 5 years, but most of those who care for individuals with dementia have never had special training.

Family members and other informal caregivers need information about the nature of the diseases and how their daily lives might change. That knowledge can improve their ability to plan and anticipate problems. They also need information about how to provide care. Persons with dementia are increasingly receiving special care, yet the results of innovations are not widely disseminated. When they are published, it is frequently in professional journals not readily available to family members. Health professionals can assist by preparing books, pamphlets, videotapes, and other educational materials intended for family caregivers. A few such materials are avail-

able: a guide to home care has been prepared, and several books have been published in recent years.

The care of someone with dementia, as with other chronic illnesses, demands a range of skills and duration of service that no individual can fully supply. That realization has led to the development of interdisciplinary teams consisting of physicians, nurses, psychologists, social workers, and others. Multidisciplinary teams can better coordinate different services and bring their various areas of expertise to bear on the problems of someone with dementia.

Physicians now in general practice have had little formal training in geriatrics, although those who graduated from medical schools recently are likely to have had some courses. Attention to dementia has increased dramatically in some specialties, particularly neurology and psychiatry. Other specialties, such as family practice and internal medicine, are also publishing more articles, developing continuing education courses, and modifying medical school and residency curricula to include more material about dementing illness. Physician training in geriatrics should be improved by supportive provisions in the Omnibus Health Act of 1986 (Public Law 99-660). The results of such efforts should be felt over the next decade.

The physician's role in dementing illness extends well beyond making a diagnosis and rendering medical treatment. It also involves interacting with the care team and referring patients and their families to support groups, social services, and long-term care agencies.

Nurses are the backbone of long-term care, but long-term care is a low prestige and low paying specialty among these professionals. A shortfall of 75,000 nurses in long-term care is projected by 1990. The medical training that nurses receive may not prepare them for the predominantly administrative and supervisory roles they perform in long-term care settings, and coverage of dementia varies among nursing schools even more than among medical schools.

Geriatric nurse practitioners, who receive special training in geriatrics, typically learn about the medical needs of older people, including coverage of dementia, and can perform many of the diagnostic, assessment, and treatment functions of physicians. They also generally learn about the service delivery system and how to coordinate services. They can form a bridge between the medical and social service systems, and are less costly to use than physicians.

Nurse's aides provide an estimated 80 to 90 percent of direct patient contact hours in long-term care. Yet they are poorly paid (usually minimum wage), have low educational levels, and have high turnover rates. Nurse's aides frequently have different socioeconomic and cultural backgrounds than those of their clients. The responsibility to train nurse's aides falls to long-term care facilities. Administrators are reluctant to invest heavily in training because aides are unlikely to remain long at the facility, but patient care depends on such training. Even those facilities that do wish to train aides have been hampered by lack of materials on dementia. Materials for training have recently become available through a cooperative ef-

The care of someone with dementia, as with other chronic illnesses, demands a range of skills and duration of service that no individual can fully supply.

fort of ADRDA and the American Health Care Association, and through the Hillhaven Corp.

Other professionals are also involved in the care of those with dementia. Complete care frequently involves social workers, psychologists, physical and occupational therapists, speech therapists, and administrators who are familiar with the problems faced by individuals with dementia and knowledgeable about available services.

The Federal Government could play a critical role in ensuring that health and social service personnel working with persons with dementia receive the education and training necessary to deliver high-quality care. This role extends to educational institutions, programs that train professionals, and facilities that provide care.

Disseminating information about care to professional networks, family support groups, and the lay press can be an important function. The role of the Federal Government in providing information is most important in those areas in which it predominates (e.g., biomedical research, health services research, and how to use government programs). One example is the Alzheimer's Resource Center of New York City, which is preparing a book on nationwide resources about dementia available through the network of Area Agencies on Aging and State Units on Aging. The effort is the result of cooperation between a local chapter of ADRDA, the New York State Department for the Aging, and the Administration on Aging.

Accreditation of educational programs that train health and social service professionals is generally performed at the State level, but it is subject to Federal guidelines for those services reimbursed by Federal monies (e.g., Medicare and Medicaid). **Licensure** of professionals is also largely a State function, subject to Federal standards. **Training and staffing** requirements for acute, mental health, and long-term care facilities are written by States subject to Federal regulations. Requiring training about the care needs of those with dementia could be incorporated into certification guidelines. Although certification is a State function, the Federal Government could make receipt of Federal funds conditional on certain certification requirements.

Direct funding of training programs for physicians, nurses, and other health professionals is supported by the Department of Health and Human Services and the Veterans Administration. Continued support, with increased emphasis on geriatrics and particularly dementia, is likely to result in faculty whose talents are multiplied by teaching others to tackle the problems related to dementia.

Delivery of Long-Term Care

Formal long-term care services for persons with dementia are provided in nursing homes, board and care facilities, day care centers, mental health facilities, or individuals' homes (see table 6). Until recently, there has been little study of which services are used or needed by persons with dementia and by their caregivers. Equally little is known about which settings are best suited to deliver many of the needed services. Some studies suggest that 40 to 75 percent of those in nursing homes have dementia; data on prevalence of dementia in other settings are unavailable.

Individuals with dementia often need personal care, chore, and homemaker services in addition to—and often more than—medical care. Personal and social services are less widely available and less likely than medical care to be covered by government programs. Families may need temporary respite from continual supervision and care, but few agencies deliver care that is intended to relieve the burden of caregivers rather than patients (although most services do both).

Who Delivers Care?

Several factors determine who delivers long-term care for persons with dementia. For any one person, care may come from family at home, day care centers, home care providers, or a nursing home. Which provider is most appropriate depends on the extent of family and community informal supports, the quality and range of available services, the individual's symptoms, and the cost of the various options.

Families play a predominant role in providing long-term care for older Americans. A General Accounting Office study of the elderly population in Cleveland conducted in 1975 concluded that families were providing more than 50 percent of all long-term care services received, and that as the impairment of the patient increased, so did the proportion of services provided by the family. For the extremely impaired group, families provided 80 percent of needed services.

The degree of informal support may diminish in coming decades, however, for several reasons. Those most at risk of developing dementia are people in their eighties, and the children and spouses of such individuals are also likely to be older and themselves at risk of disability. At the same time, the declining birth rate in the United States has reduced the proportion of those who will be available to care for tomorrow's older people. The rapid influx of women into the work force also portends reduced availability of family caregivers; although women today report that work is important, one study found that they act as though they give caregiving priority over employment in most cases. Rising divorce rates and remarriage rates also complicate determining who will render care to an older relative; a person newly married into a family may feel less obliged to care for the new spouse's parent with dementia. Finally, the growing mobility of families increases geographic dispersion, and may make family caregiving less likely. Each of these trends weakens the informal care system, and may increase dependence on government services.

The primary needs of informal caregivers are: 1) respite care, 2) information about the diseases and care methods, 3) information about services, and 4) a broadened range of services.

Caregiver Support

The primary needs of informal caregivers are respite care, information about the diseases and care methods, information about services, and a broadened range of services. **Family members' efforts can be aided by the Federal Government by giving them optimal information (especially that arising from federally supported research), assisting them in finding out about or obtaining services, and extending some benefits to caregivers and the person needing care as a unit, rather than restricting them to the individual with dementia.**

Range of Services

Caregivers believe that more services should be available to care for individuals with dementia. The caregiver survey conducted for OTA found that the majority of those who listed respite care, adult day care, board and care, and nursing home care as "essential" either knew these services were not available or did not know if they were available. That finding suggests that there is an unmet need both for services and for information about them.

Increasing the number of choices for care of persons with dementia will not necessarily diminish demand for nursing home care or reduce institutional care costs borne by government. Day and home care is much more widely available in the United Kingdom, for example, but rates of nursing home residency are not significantly lower. Community-based care has not led to cost savings over nursing home care according to many recent studies. Some studies, however, report better patient outcomes with home care, and—of particular importance for persons with dementia who tend to reside for long periods in nursing homes once admitted—studies have not predicted what "the benefits of coordinated, expanded home care services might be for older, chronically impaired individuals who do not meet the skilled care requirement but, rather, need ongoing maintenance care".

Patient Assessment and Eligibility for Services

Assessment is the process of identifying, describing, and evaluating patient characteristics associated with illness. While diagnosis of a dementing illness identifies the disease, assessment describes its impact on the individual, quantifies its severity, and is therefore essential in determining long-term care needs.

Eligibility for Medicare and Medicaid long-term care services and reimbursement levels for covered services are based primarily on the medical

and nursing care needs of the individual. Some States are now using assessment instruments that measure cognitive and behavioral deficits and limitations in activities of daily living to determine Medicaid eligibility or reimbursement levels. These case mix assessments can reduce incentives to discriminate against heavy care patients, but have not been rigorously studied to ascertain their impact on persons with dementia. The RUG-II classification system in New York, for example, places 22 percent of those with diagnoses indicating dementia into the least reimbursed category. That placement could be either because these people indeed have only minimal disability (and might be better cared for outside a nursing home), because the diagnosis is incorrect, or because the RUG-II assessment process does not accurately capture the disabilities of such individuals.

Other case mix assessments may retain that uncertainty for those with dementia. It is important to determine whether the individuals do not need to be in a nursing home or whether their needs are not being identified by the assessment procedure, because low reimbursement will incline nursing homes against admitting individuals who fall in the minimal disability category. In New York, that has already occurred, with a marked drop in admissions of those showing minimal disability as measured by RUG-II assessment. It will be important to find out if those with dementia constitute a large fraction of that group and if there are alternative methods of care for those not admitted to nursing homes.

The assessment process is often the starting point for planning services, educating family members, and referring people to support groups and other community resources. Early engagement of a formal assessment process can thus serve as a focal point for bringing health professionals and families together to determine the prognosis for the individual with dementia, to learn about care options, and to find sources of relevant information.

Special Services for Individuals With Dementia

An increasing number of long-term care facilities and agencies are developing special services for persons with dementia, but these services are not yet widely available and most such individuals are treated elsewhere. Preliminary data suggest that **1 to 2 percent of nursing home residents with dementia are in special care units**. These facilities appear to be raising the standard of care, and are focusing attention on the large subpopulation of nursing home residents who suffer from dementia. Special care involves training of nurses and aides, redesign of rooms and common areas, and activities intended to take advantage of spared mental functions. Adapting the environment to altered needs of those with dementia appears to be useful, but the optimal way to do so is a topic of debate. The number of special care units has increased dramatically in recent years, yet no national body is responsible for identifying them, coordinating studies (to reduce duplication and disseminate results rapidly), or evaluating their efficacy.

Several policy issues are raised by special care units and programs. First, there is an apparent shortage of people highly knowledgeable about dementia available to staff such units or evaluate them. Second, evaluation

Diagnosis of a dementing illness identifies the disease, and assessment describes its impact on the individual, quantifies its severity, and is therefore essential in determining long-term care needs.

and coordination of different units is currently haphazard. Third, standards for quality are unclear. Fourth, the type of individual eligible for care on special units is not uniform among different units, and optimal care methods may differ according to severity, type of symptoms, or disease. Finally, the costs and fair reimbursement rates for special units merit further inquiry. Do special care units cost more? Should they be paid more to care for those with dementia? Will special reimbursement lead to inequitable treatment of other types of patients, or will failure to pay more for those with dementia diminish their care?

Quality Assurance

Persons with dementia are at particular risk of receiving substandard care. They cannot communicate effectively, and their complaints may be discounted or ascribed to mental instability or misunderstanding. Reduced intellectual abilities interfere with rational consumer choice, an important component of quality assurance. Family members can act on behalf of individuals with dementia to assess and ensure the quality of care. If they are not available or the family is not cohesive, then ombudsmen, case managers, or designated surrogates must do so.

Quality of care in hospitals paid by Medicare is subject to the review of Professional Review Organizations. Outpatient and ambulatory acute care are less subject to direct inspection. The threat of malpractice is a strong incentive for providing adequate care in most acute care settings, but it has not been widely applied in long-term care settings.

The quality of care in nursing homes is regulated by States, subject to certification standards for Medicare and Medicaid. The system for assessing quality under Medicaid and Medicare is changing from a focus on inspection of facilities and physical plant to one that adds a client-centered assessment. Residents with dementia, however, are unlikely to be able to answer many of the questions about quality; inspection of their physical condition will yield clues as to their physical care, but will not assess overall quality of staff interactions or the resident's emotional satisfaction and staff regard for the person's dignity. These concerns are difficult to solve through purely regulatory means. Family assessment of a relative's health and happiness is another means of quality assurance. It is not available to residents without families, however, and its efficacy hinges on facilities' willingness to attend to suggestions or the availability of alternative care settings if they do not.

For Medicare and Medicaid administrators, only limited options exist to ensure compliance with care standards. In many areas, the scarcity of nursing home beds makes moving out of a poorly managed facility an unattractive option for the resident because an alternative one may not be available; that same scarcity makes State agencies reluctant to close down facilities. Less stringent enforcement actions have been successful in some States, and legislation permitting more use of them might be useful. Professional organizations (e.g., American Health Care Association and the American Association of Homes for the Aging), proprietary and nonprofit nursing home chains, and new programs in teaching nursing homes can also promote higher standards and adherence to existing standards.

Day care, home care, board and care, and other community-based settings are licensed and regulated much less than nursing homes. Information about quality in such settings is sparse and much less thoroughly analyzed than information regarding quality of care in hospitals or nursing homes. Payment levels are generally lower and tend to be direct rather than through public subsidy, making any government regulation beyond licensing unlikely. Family or case manager assessment of quality is thus the main assurance of quality, perhaps supplemented by final resort to the legal system. Organizations (e.g., the National Association for Home Care and the National Council on the Aging) can help develop guidelines for care and suggest means of quality assurance. Federal and State Governments could also choose to have a direct role. If the range of services is expanded, examination of the quality of care in day care, home care, and board and care settings would be an important topic for health services research—to identify innovative ways to ensure that individuals have quality care that respects their rights and preserves their dignity.

Financing Long-Term Care

Financing long-term care for persons with dementia is one of the policy issues of greatest concern to caregivers and policymakers, and about which there is the least consensus. Policy options fall into several groups, according to the range of services reimbursed; the source of payment (individual, Medicaid, Medicare, insurance); and the relative responsibility of individuals and government.

These factors are woven together in a confusingly complex fabric of existing policies and priorities. Caregivers would prefer to see an expanded range of services available, whatever the source of payment. Government program administrators, legislators, and insurers also wish to fund the broadest number of options, but they do not want to leave commitments open-ended or to pay for services used by those who do not need them. The extremely complex set of laws, regulations, and contract arrangements for long-term care services reflects that concern for overutilization. Restricting payment to institutional settings has been one way to discourage illegitimate use and to attempt to concentrate resources on those who most obviously need them.

The source of payment determines not only who pays but also which services are covered and how those services are regulated and financed.

Special care units appear to be raising the standard of care and are focusing attention on the large subpopulation of nursing home residents who suffer from dementia.

Acute care under Medicare, for example, is paid under the diagnosis-related group payment system in most States, covers only some medically necessary services, and is relatively uniform—from the point of view of the individual—throughout the United States. Medicaid, in contrast, varies tremendously among the States in its eligibility criteria, funding levels, extent of coverage of nonmedical services, access to home services, method of payment, and enforcement of quality standards—for both acute and long-term care.

Options for financing long-term care also differ in degree of public subsidy, ranging from complete private financing to heavy public subsidy. At one end of the scale, private financing would include:

- direct individual or family payments not derived from government income programs,
- group cooperatives (for bargaining reduced rates with providers and insurers),
- charities, and
- conversion of home equity or other illiquid assets.

Numerous options that combine private financing with indirect public subsidy have been suggested:

- direct payments derived in part from government income programs;
- volunteer programs (generally by tax-subsidized nonprofit organizations, but also including government aid as in ACTION's Senior Companion programs);
- social/health maintenance organizations (S/HMOs);
- cooperatives (composed of groups of individuals with similar needs either directly providing care on a mutual help basis, directly financing services, or sharing information about services and financing options);
- private long-term care insurance (tax-subsidized);
- life care communities (tax-subsidized);
- dependent care tax deductions or tax credits; and
- individual medical or retirement accounts (tax-subsidized).

Finally, financing could involve increased direct public subsidy, with individuals contributing partial costs through expanded Medicaid eligibility, range of services, or level of payment, and through Medicare coverage of long-term care services.

Policy changes affecting Medicaid and Medicare could involve either small incremental changes in eligibility, scope of services, or reimbursement mechanisms or major long-term care reform. Major reform might entail private

options dovetailed to public programs, publicly managed voluntary insurance options, or mandatory long-term care coverage. Options that extend complete public subsidy of all costs have not been discussed because proposals for such programs are not before the U.S. Congress.

The full range of policy options is covered in the report of the OTA workshop held in May 1986, to be released by the Senate Committee on Labor and Human Resources and the House Select Committee on Aging. In addition, reports on long-term care financing are expected from the Brookings Institution and the Congressional Budget Office.

Secretary of Health and Human Services Otis Bowen transmitted a report on catastrophic illness to the President in November 1986. That report discussed acute medical care and also recommended several changes to improve long-term care financing, noting that "long-term care is the most likely catastrophic illness risk faced by individuals and families." Long-term care recommendations included: 1) Federal and private support for a broad educational effort regarding risks, costs, and options; 2) establishment of Individual Medical Accounts and withdrawal provisions for Individual Retirement Accounts; and 3) support for private long-term insurance through tax provisions and removal of employer disincentives to cover long-term care in health insurance plans. Preparation of the report involved several public hearings in different regions, deliberations by three committees, and is based in part on a report to the Secretary by the Private/Public Sector Advisory Committee on Catastrophic Illness.

Financing of long-term care is one of the issues affecting individuals with dementia (and their families) that is most sensitive to public policies. Through Medicaid, Federal and State Governments are important payers of long-term care, covering the majority of those in nursing homes. The amounts paid by State and Federal Governments for nursing home care are roughly equal to total payments by individuals. The American Health Care Association estimates that 70 percent of nursing home residents are covered by Medicaid, and the figure is well over 80 percent for some States. The proportion of patients covered by Medicaid is higher than its fraction of payments for two reasons:

1. some patients on Medicaid also receive some income (from social security or other sources) that is paid to the facility to reduce Medicaid payments, and
2. levels of reimbursement per person are generally lower through Medicaid than other sources of payment.

The dominance of Medicaid means that decisions about the Medicaid program have a great effect on how nursing homes operate. Policies affecting nursing home coverage under Medicare affect a smaller, but still significant, fraction of nursing homes. Because of the absence of private insurers in long-term care, Federal and State Government decisions about financing are pivotal in determining access to and availability of day care, home care, respite care, and other services outside nursing homes.

Persons with dementia are at particular risk of receiving substandard care. They cannot communicate effectively, and their complaints may be discounted or ascribed to mental instability or misunderstanding.

Biomedical Research

Biomedical research includes basic biological, clinical, and public health research. It roughly corresponds to the type of research conducted under the auspices of the National Institutes of Health (either directly or through universities and medical centers). Basic research is conducted in the pursuit of scientific knowledge without primary regard for the applications of such knowledge. Clinical research applies basic knowledge in the search for preventive measures, treatments, and methods of diagnosis. Public health research builds on both basic and clinical research and applies it to population aggregates. The most common type of dementia, Alzheimer's disease, cannot be prevented or its symptoms reversed with current knowledge and techniques. The severity of future medical and social problems could be dramatically reduced if an effective drug or surgical treatment were found to significantly reduce symptoms or arrest the disease. Only a small proportion of those expected to develop dementia now have it, so finding a means of prevention could drastically reduce the projected number of people affected.

NIA, NIMH, and NINCDS are the three primary agencies supporting biomedical research (see table 8). Federal support for biomedical research (excluding funding for the Administration on Aging (AOA) and the Health Care Financing Administration (HCFA), whose research is primarily on health service delivery) has gone from less than $4 million in 1976 to over $65 million estimated for 1987. The number of publications on "Alzheimer's disease," "dementia," and "senility" leapt from 30 in 1972 to 87 in 1976, and then to 548 in 1985, reflecting the importance of increased Federal support. Nongovernment organizations such as ADRDA, the John Douglas French Foundation on Alzheimer's Disease, the American Federation for Aging Research, and the Howard Hughes Medical Institute are also contributing research funds, at levels corresponding to 5 to 10 percent of Federal funding. Private pharmaceutical and medical products companies are supporting applied research to find effective drugs and diagnostic devices, but their work builds on the basic research supported by the Federal Government.

Biomedical research on dementing conditions is likely to yield benefits in addition to its clinical applications. Knowledge of the brain is still scant

Table 8.—Federal Funding for Research on Dementia, 1976-87
(thousand dollars)

Agency[a]	1976	1977	1978	1979	1980	1981	1982	1983	1984	1985	1986[b]	1986[c]	1987[d]
NIA	857	1,500	1,960	4,142	4,211	5,196	8,054	11,848	21,456	28,830	34,048	32,691	40,760
NINCDS	2,314	2,333	2,422	2,844	4,960	5,427	6,243	8,678	11,700	12,826	14,030	13,427	15,900
NIMH	728	815	790	1,315	2,151	4,700	4,800	5,000	5,600	5,750	6,000	5,750	6,000
NIAID	—	—	—	1,381	1,775	1,394	1,256	1,041	1,336	1,211	1,247	1,192	1,412
DRR	—	—	—	—	—	—	—	604	709	1,034	1,055	1,010	1,062
ADA	—	—	—	—	—	—	—	—	164	1,128	900	627	600
HCFA	—	—	—	—	—	—	—	—	—	—	—	—	1,200
Total DHHS	3,899	4,648	5,172	9,682	13,097	16,717	20,353	27,171	40,965	50,779	57,280	54,697	66,934

[a]NIA (National Institute on Aging), NINCDS (National Institute on Neurological and Communicative Disorders and Stroke), NIMH (National Institute of Mental Health), NIAID (National Institute on Allergy and Infectious Diseases), DRR (Division of Research Resources, National Institutes of Health), ADA (Administration on Aging), and HCFA (Health Care Financing Administration). All agencies are in the U.S. Department of Health and Human Services.
[b]Appropriated by Congress in Public Law 99-178.
[c]Estimates following sequestration of funding under the Deficit Reduction Act of 1985.
[d]Estimates based on Continuing Resolution appropriations for Fiscal Year 1987 (P.L. 99-500), with individual figures taken from agency budget offices and direct appropriations.

SOURCE: National Institute on Aging Budget Office, 1986; National Institute of Mental Health Budget Office, 1986; and *Progress Report on Alzheimer's Disease: Volume II*, NIH Publication 84-2500, July 1984, modified by the Office of Technology Assessment in light of fiscal year 1987 appropriations. Estimates obtained from individual agency budget offices for years 1986 and 1987.

in comparison to the size of the task, and the study of the nervous system—neuroscience—is one of the most exciting areas in biology today. Support for research on dementing conditions will likely support work that will increase such knowledge in these disciplines. Research on dementia could, in fact, become a focus for neuroscience, just as cancer research led to many important advances in molecular biology and the spawning of biotechnology.

Major successes in biomedical research could also substantially reduce the costs and projected social and personal burdens of dementia. In other areas of research, successful prevention or treatment may actually lead to *increased* health care costs (e.g., a death prevented in middle age can increase aggregate costs because the person lives longer to have more episodes of ill health, each of which involves costs). Prevention or effective treatment of dementing disorders is likely to be highly cost-effective in the long term because the financial impact is severe, chronic, and occurs at the end of life. An effective means of preventing Alzheimer's disease would, for example, dramatically reduce the need for nursing homes and costly medical care without necessarily leading to substantially longer life or new medical problems. Other medical problems would likely cost less, rather than more.

An exclusive focus on biomedical research is unwise, however. Although increased funding makes scientific discoveries more likely, such discoveries will not necessarily lead to a means of prevention or cure, diagnostic tests, or even effective treatments. The consequences of new scientific findings may not be known for several decades, and may only much later improve clinical care. Scientific problems posed by disorders causing dementia are

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likely to yield to scientific inquiry, but public policy that presumes a revolution in care methods--based on discoveries not yet made --is not advisable.

Health Services Research

Health services research, as it applies to the subject of this report, is the multidisciplinary study of those with dementia and of the systems that serve them. It includes the community and family, but excludes biomedical research. Some types of research, such as epidemiology and patient assessment, bridge the gap between health services and biomedical research. Study of how to care for individuals, especially evaluation of methods that do not employ drugs or medical devices, is included in health services research, although some elements are also clinical. Topics range from studying how best to care for persons with dementia (at home, in nursing homes, or in day care centers) to evaluating different methods of paying for long-term care services.

Health services research tends to be supported by different agencies than biomedical research, although there is some overlap (NIMH and NIA, for example, mainly support biomedical research but are also among the agencies providing the most support for health services research on dementia). The type of information derived from health services research is crucial to rational planning of public policy and informed consumer choice. One analyst has observed, however, that "public policy is hampered by the woeful state of information about almost all social aspects of senile dementia and the deplorable quality of studies of intervention effects".

Health services research related to dementia was the topic of an OTA workshop held in February 1986, cosponsored by the Subcommittee on Aging of the Senate Committee on Labor and Human Resources, the Human Services Subcommittee of the House Select Committee on Aging, and ADRDA. Results of that workshop are summarized here, and are discussed more fully in another document available through the Senate Committee on Labor and Human Resources and the House Select Committee on Aging. Discussions at that workshop revolved around six general topics:

1. epidemiology,
2. patient assessment,
3. service needs,
4. availability of and access to services,
5. cost of care, and
6. quality assurance and measurements of outcome.

Several points of consensus emerged at the workshop. First, dementing disorders are a substantial problem for the health care system, particularly in long-term care. Second, little is known about them in any setting. Third, data have been gathered that might shed light on current policies, but the data have not been analyzed with a view to discerning the needs of the large number of individuals who have dementia. Finally, there is a need to intensify the study of health care delivery to individuals with dementia and their families.

The few studies of health services that have focused specifically on the needs of individuals with dementia stand in stark contrast to the amount of information about treatment of specific groups of comparable size in acute care (e.g., persons with diabetes). That lack reflects both a general paucity of information about long-term care services, and a failure of long-term care studies to focus on the large subpopulation with dementia.

Many recent and ongoing efforts to gather data about long-term care do contain information about individuals with dementia. No single survey is ideal in assessing needs, disabilities, severity of cognitive impairment, and availability of informal supports, but "the breadth and depth of the information collected across the data sources . . . suggest that a substantial understanding of health service questions . . . could be acquired by analysis of the data sets". Efforts to analyze such data sets would be much less costly than beginning extensive new surveys, and could answer some important questions and identify other key ones to address in future demonstrations. Some questions are not addressed, however, in available data sets (e.g., whether special care is effective or economical, or the long-term impact of respite care on family stress, functional disability, and costs). Analysis of such questions will require new demonstrations, but these should start from the most sophisticated understanding of current data available.

Several important questions about long-term care need to be resolved before prudent public policy on health services can be enacted. It is frequently argued, for example, that in-home services can help physically and cognitively impaired people to remain in their homes. Yet a growing body of evidence indicates that expanded use of in-home services does not generally reduce the need for nursing home beds. Such research has failed to separately analyze those with and without dementia, to focus on specific target groups, or to concentrate on long-stay patients whose needs are more supervisory than medical. Persons with dementia fall into the groups about which there is the least information—those needing supervisory care for long periods rather than "skilled" care for short periods. It is thus unclear whether in-home and other respite services will supplement, supplant, or increase nursing home care for those with dementia. Special attention to this group may prove crucial to designing long-term care services in general.

A large proportion of nursing home residents, particularly long-stay residents, are individuals with dementia who require 24-hour supervision, a service that is not generally offered in the home. Conversely, persons needing long-term care but not 24-hour supervision (e.g., those with arthritis or paralysis due to stroke) may benefit greatly from home care services but are less likely to be in a nursing home. The lack of correlation between

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availability of home services and reduction of nursing home care may thus be explained, at least in part, as use by different types of individuals. Only further study of long-term care service delivery in various settings can resolve that and other questions of interest to providers and policymakers.

Research on delivery of care can build on efforts by States, long-term care providers, and family support groups, but Federal coordination would be useful to reduce needless duplication of effort, to ensure wide dissemination of relevant results (a clearinghouse function), and to maintain sufficient focus on Federal issues (e.g., quality assurance, cost containment, and payment).

Health services research will determine the future basis for public and private activities in financing, quality assurance, training, and service delivery to persons with dementia. Research in this field does not necessarily depend on projects including only individuals with dementia. Evaluation of more general long-term care demonstrations can shed light on how those with dementia use such care. HCFA is supporting a study of reimbursement in the State of Texas, for example, that covers a sample of all nursing home patients, not just those with dementia. A part of the information gathered will include assessment of cognitive status that can be compared with existing studies on those with dementia in the community. That study should permit an evaluation of the influence of cognitive impairment per se, which has not been previously possible.

Federal spending for health services research in 1984 reached $200 million. That was one-twentieth of 1 percent of total health care spending that year ($387 billion), one-fifth of 1 percent of Federal health care spending ($111.9 billion), and 3.2 percent of the Federal budget for biomedical research ($6.15 billion). A survey of Federal agencies supporting health services research on dementia was conducted in April 1986 by the Congressional Research Service. The survey found that AOA was funding 12 projects, with the following spending history: $163,817 for two projects in fiscal year 1984; $1,127,618 for 12 projects in fiscal year 1985; and $431,400 continuing and $500,000 planned new spending in fiscal year 1986. NIA was planning $426,000 for fiscal year 1986. NIMH was funding three health service research projects that would include a component focused on dementia in fiscal year 1983, four in fiscal year 1984, seven in fiscal year 1985, and seven in fiscal year 1986, but the budget specific to dementia was not estimated. AOA, NIMH, and HCFA were each soliciting proposals for research that included analysis of health services for those with dementia. The National Center for Health Services Research (NCHSR) and Health Care Technology Assessment had not funded specific research and was not soliciting projects.

Estimated Federal spending on health services research related to dementia was thus in the range of $1.3 million to $2 million in 1986. That corresponds to roughly one-two-hundredth of 1 percent of the estimated national costs of dementing illness ($24 billion to $48 billion), one-thirtieth of 1 percent of Federal payments for long-term care of those with dementia ($4.4 billion), and 3 percent of biomedical research on dementia ($54 million).

The need for information about long-term care of those with dementia in order to plan national health policy has prompted Congress to fund research in this area. The final column in table 8 shows the estimated levels of research funding provided by the Continuing Appropriations for fiscal year 1987 (called the "continuing resolution"—Public Law 99-500). The bulk of funding is for basic and clinical research, but also includes $1.2 million for HCFA to develop and fund three demonstration projects on respite care for families of those with Alzheimer's disease and related disorders. The Omnibus Budget Reconciliation Act of 1986 (OBRA—Public Law 99-509) authorizes up to $40 million to create 5 to 10 regional centers to diagnose and treat individuals with Alzheimer's disease and related disorders. Funding will come from Medicare payments for those already Medicare eligible. (The continuing resolution limits funding for demonstration projects under Medicare, and a few experts contacted by OTA believe that this limit might apply to the Alzheimer's disease diagnosis and treatment centers. Most consulted, however, believed that the restrictive language would not apply, and the centers would be funded as specified in OBRA.) OBRA also authorized $1 million for fiscal year 1987, and $2 million in each of the three following years, to develop a respite care demonstration program in New Jersey under the State's Medicaid program.

HCFA funding for health services research will be supplemented by a group of projects supported by a combination of private and government sources. The Robert Wood Johnson Foundation, Administration on Aging, and ADRDA are jointly planning a competitive grants program. They intend to support the development of dementia service delivery demonstration projects in a number of communities throughout the Nation.

The last piece of legislation passed by the 99th Congress (Public Law 99-660) includes the Alzheimer's Disease and Related Dementias Services Research Act. This law establishes a Council on Alzheimer's Disease within the Department of Health and Human Services (making permanent the Task Force on Alzheimer's Disease), an Advisory Panel on Alzheimer's Disease (composed of 15 citizens appointed by the Director of the Office of Technology Assessment), a new group of awards for achievement in research to be bestowed by the Director of NIA, and an information clearinghouse to disseminate information about Alzheimer's disease—also administered by NIA. The act authorizes health services research to be conducted by NIA, NIMH, NCHSR/HCTA, and HCFA (beginning in October 1987) and mandates educational programs for the Social Security Administration (regarding disability policies related to dementia) and training of safety and transportation personnel about special problems in dealing with individuals who

have dementia. It also authorizes increased support for training in geriatrics. Several of the provisions of the new law can go into effect without further action. The research programs and other activities authorized by the act will, however, depend on new appropriations in the 100th Congress.

NOTE: Copies of the report "Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias" can be purchased from the Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402-9325, GPO stock No. 052-003-01059-3.

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